

# NORWEGIAN VALIDATION OF THE PEDIATRIC EVALUATION OF DISABILITY INVENTORY (PEDI)

**Assessing children's ADL skills**

**Doctoral thesis  
by  
Marie Berg**

Department of General Practice and Community Medicine  
and  
Sunnaas Rehabilitation Hospital  
Faculty of Medicine  
University of Oslo



Daniel, 9 år



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## ABSTRACT

Activities of Daily Living (ADL) are among the first achievements in childhood, and provide a sense of mastery, independence and social approval for the child. Self-dependence in everyday living skills is important to everyone, not least for children with disabilities. The Pediatric Evaluation of Disability Inventory (PEDI), is a widely used functional assessment and an evaluative tool of ADL skills intended for children with a disability, originally designed for use in the U.S.A.

*Aim:* The overall objective of this thesis was to translate the American PEDI into Norwegian and to assess the applicability and validity of the Norwegian version. The specific research questions investigated were if the Norwegian version of the PEDI is functionally equivalent to the American version, reliable in relation to inter-rater, intra-responder, and intra-rater reliability, and useful according to US normative data for a general Norwegian population.

*Method:* Guidelines for cross-cultural adaptation were used in translating the Norwegian version of the PEDI. A pilot study based on cross-sectional principles of the Norwegian version was investigated in a small, but carefully selected, sample. A population-based cross-sectional study evaluated the applicability of PEDI American normative data for a general Norwegian population. Rater agreement was investigated.

*Results:* The results confirmed the Norwegian version of the PEDI's translational equivalence with the original American version and reliability of measures. However, the results showed that the Norwegian sample scored significantly lower than US reference values, especially for self-care skills. Capability and caregiver assistance mean values ranged from 38.0 to 46.8 for self-care, mobility and social function against an expected mean of 50. For mobility and social function the results were of less significance.

*Conclusion:* The age-norms for the PEDI deviated from the American normative values, and need adjustment to fit the Norwegian culture. However, PEDI has the particular feature to report outcomes in two scales: normative scores and scaled scores. The scaled score provides a criterion referenced indication of the child's ability to perform the total amount of tasks in the PEDI and is not adjusted for age. The scaled score describes and measures the function of children, and is relevant and useful in a Norwegian setting.

## **LIST OF PAPERS**

The thesis is based upon the following papers. In the text they will be referred by their Roman numerals.

- I.** Berg M, Jahnsen R, Holm I, Hussain A. Translation of a multidisciplinary assessment – Procedures to achieve functional equivalence. *Advances in Physiotherapy* 2003; 5: 57-66.
- II.** Berg M, Frøslie KF, Hussain A. Applicability of Pediatric Evaluation of Disability Inventory in Norway. *Scandinavian Journal of Occupational Therapy* 2003;10: 118-126.
- III.** Berg M, Jahnsen R, Frøslie KF, Hussain A. Reliability of the Pediatric Evaluation of Disability Inventory (PEDI). *Physical & Occupational Therapy in Pediatrics* 2004; 24(3): 61-77.
- IV.** Berg M, Aamodt G, Stanghelle J, Krumlinde-Sundholm L, Hussain A. Cross-cultural validation of the Pediatric Evaluation of Disability Inventory (PEDI) norms in a randomized Norwegian population. Submitted.

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## ABBREVIATIONS

ADL	Activities of daily living
AMPS	Assessment of Motor and Process Skills
COPM	Canadian Occupational Performance Measure
ICC	Intra-class correlation coefficient
ICF	International Classification of Functioning, Disability and Health
ICF-children	International Classification of Functioning, Disability and Health Children and Youth
ICIDH	International Classification of Impairments, Disability and Handicap
GAS	Goal Attainment Scale
OT	Occupational therapist/therapy
PEDI	Pediatric Evaluation of Disability Inventory
SE	Standard Error
SEM	Standard Error of Measurement
TIME	Toddler and Infant Motor Evaluation
VABS	Vineland Adaptive Behavior Scale
WeeFIM	Functional Independence Measure for Children
WHO	World Health Organization

## 1.1 INTRODUCTION

Activities of Daily Living (ADL) are among the first achievements of childhood, and provide the child with a sense of mastery, independence and social approval. Activities of daily living include self-care functions such as eating, dressing, bathing, grooming and mobility (1).

Children are expected to develop independence in their performance of everyday living skills, and young children demand it: "I can do it myself". Self-dependence in everyday living skills is important to everyone, and no less so to children with disabilities (2). Delay and inability to perform a skill are major barriers for participation in family life, play, kindergarten/school and in society in general. Contextual factors influence the development of ADL skills. The environment's attitudes, as well as physical factors in the environment, can facilitate or hinder functioning for children with special needs.

Many children with disabilities do not automatically develop independence in ADL skills, and benefit from intervention from rehabilitation services to achieve a higher degree of independence and/or autonomy in everyday living skills. A systematic assessment of how children with disabilities function in an everyday context at home is necessary to plan meaningful and realistic interventions. Outcome measures need to be related to functional ability and integration in the community to secure optimal participation in everyday life activities for children with disabilities (3). Standardized assessment tools with good content and evaluative validity are needed, which can guide treatment planning, measure clinical change and provide a reliable basis for describing the child's status. The Pediatric Evaluation of Disability Inventory (PEDI) is a multidisciplinary tool which is highly appreciated in pediatric occupational and physical therapy, judging from its widespread use. The PEDI meets the requirements for valid and reliable outcome measures (4), and was translated to Norwegian by four researchers in 2000, with permission from the PEDI research group (5).

Living conditions in Norway seemingly do not differ from the US western life style, and it could be assumed that US age norms could be useful in Norway. However, development of skills in everyday life is influenced by personal, social, cultural and environmental factors besides the child's age and maturation. To enable interpretations of norm-referenced results, both for individuals and to facilitate comparison of health care in different countries, measures need to work in a consistent manner across cultures (6).

Cross-cultural validation provides evidence of possible variability related to age norms and items responses. The purpose of this thesis was to investigate the validity of the American PEDI for a general Norwegian population.

## **1.2 PEDI**

The PEDI (4) was developed as a functional assessment and an evaluative tool for children with disability from 6 months to 7 ½ years of age, and was originally designed for use in the U.S.A. The PEDI, usually administered as a structured parent interview, provides a systematic assessment and can serve as a basis for treatment planning. It is related to the child's self-care, mobility and social functioning. The PEDI is a commonly used functional assessment for children and is described as a "gold standard" assessment for children with disability (7,8). The instrument measures capability and caregiver assistance for selected functional activities within the domains of self-care, mobility and social functions on three scales: I. Functional skills (current capability of selected tasks). II. Caregiver assistance (the extent of help the caregiver provides). III. Modifications (i.e. environmental or technical modifications needed to enhance the child's function). Table I gives an overview of the content of the PEDI and PEDI scales, and is adopted from the PEDI manual (4).

**Table I** Content of the PEDI and PEDI scales

PEDI domains	Functional Skills Scale		Caregiver Assistance Scale		Modification Scale
	Subscales	Items	Subscale	Items	Items
Self care	Food Textures	4	Eating		
	Use of utensils	5			
	Use of drinking containers	5			
	Toothbrushing	5	Grooming		
	Hairbrushing	4			
	Nose Care	5			
	Handwashing	5	Bathing		
	Washing Body and Face	5			
	Pullover/Front-Opening Garments	5	Dressing upper body		
	Fasteners	5			
	Pants	5	Dressing lower body		
	Shoes/socks	5			
	Toileting task	5	Toileting		
	Management of bladder	5	Bladder Management		
	Management of bowel	5	Bowel Management		
	Sum items	73		8	8
Mobility	Toilet Transfers	5	Chair/Toilet Transfers		
	Chair /Wheelchair Transfers	5			
	Car Transfers	5	Car Transfers		
	Bed Mobility/Transfers	4	Bed Mobility/Transfers		
	Tub Transfers	5	Tub Transfers		
	Indoor Locomotion Methods	3	Indoor Locomotion		
	Indoor Locomotion: Distance/Speed	5			
	Indoor Locomotion: Pulls/Carries	5			
	Objects				
	Outdoor Locomotion: Methods	2	Outdoor Locomotion		
	Outdoor Locomotion: Distance/Speed	5			
	Outdoor Locomotion: Surfaces	5			
	Upstairs	5	Stairs		
	Downstairs	5			
	Sum items	59		7	7
Social function	Comprehension of Word Meanings	5	Functional comprehension		
	Comprehension of sentence complexity	5			
	Functional Use of Communication	5	Functional expression		
	Complexity of Expressive Communication	5			
	Problem-resolution	5	Joint problem-solving		
	Social interactive play (adults)	5			
	Peer interactions: (child of similar age)	5	Peer play		
	Play with objects	5			
	Self information	5			
	Time orientation	5			
	Self-protection	5	Safety		
	Community function	5			
	Sum items	65		5	5
Format	Dichotomous scale		6-point ordinal scale	4-point ordinal scale	

Three different scores are derived from the measurement scales in the assessment (4):

1. *Normative standard scores.* Standardization of the PEDI is based on a normative sample of 412 non-disabled American children and validated in relation to 102 disabled children. The assessment includes different sets of reference values. For all items, there are tables which indicate the age range (years) at which 10/25/50/75/90% of children are expected to master the items. The normative standard scores are constructed to have a mean of 50 and a standard deviation of 10 in each age group. Ranges of standard scores, and means and standard deviations for each 6-month age group are listed in the PEDI manual. The normative standard scores provide an indication of the child's age-related skills related to functional skills and caregiver assistance, and can be used to identify children with functional delay, as few non-disabled children are expected to have normative standard scores below 30. This scale provides norm-referenced scores.
2. *Scaled scores.* This scale provides an indication of the child's ability to perform the total amount of tasks required in the PEDI. The different tasks are rated along a continuum of relatively easy to relatively difficult items for each domain of self-care, mobility and social function. The range of possible scaled scores is 0-100, where zero corresponds to inability to succeed on any item of the PEDI, and 100 corresponds to the child's ability to do all PEDI items. The scaled score is not adjusted for age and can be used to describe how children of any age function related to functional skills and caregiver assistance, including those above 7.5 years of age. This scale provides criterion-referenced scores.
3. *Modifications scores.* The Modification Scale is a frequency count and not a measurement scale. Scores are based on frequency counts of modifications in caregiver assistance, and classify the type and frequency of the modifications.

Frequency totals for the four levels of modifications can be summarized. Guidelines for scoring are given in Table II, Measurement scales, adopted from the PEDI manual (4). All the items have specific descriptions, and the manual needs to be consulted for individual item-scoring criteria.

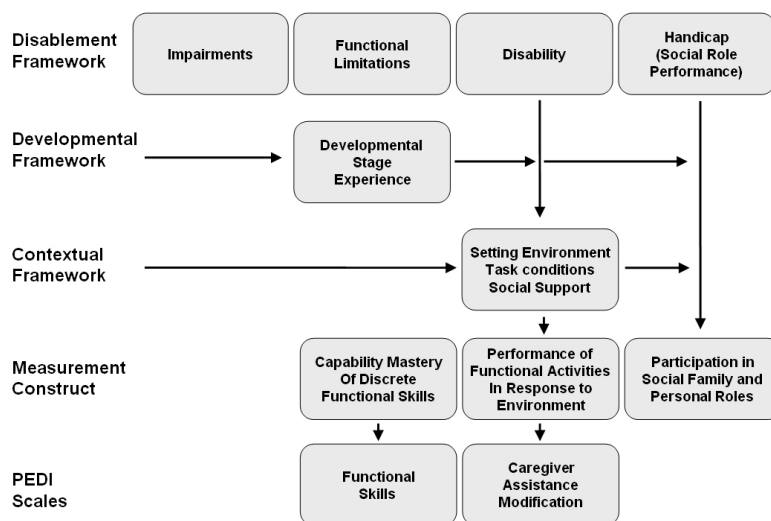
**Table II** Measurement scales

Functional Skills: Self-care, Mobility, Social Function scale	
0	Unable, or limited in capability to perform item in most situations
1	Can perform: the child is capable of performing the task in most situations or behaviors previously mastered but not longer required or used.
Caregiver Assistance: Self-care, Mobility, Social Function scale	
5	Independent: Caregiver provides no physical assistance or supervision
4	Supervision/Setup: Caregiver provides no physical help during the activity, but supervises the performance
3	Minimal Assistance: Caregiver does less than half the effort, the caregiver provides very little assistance
2	Moderate Assistance: Caregiver does more than half the effort, caregiver provides substantial assistance
1	Maximum Assistance: Caregiver does more than half of the effort, child provides meaningful assistance.
0	Total Assistance: Caregiver does almost all of the activity, child provides no meaningful assistance.
Modifications: Self-care, Mobility, Social Function scale	
N	No Modifications
C	Child-oriented (non-specialized) modifications, commonly used by all children
R	Specialized rehabilitation equipment not normally needed by non-disabled children
E	Extensive modifications such as architectural modifications or wheelchair

### 1.3 Frames of references

The development of an assessment needs to be based on a clear conceptualization of what is to be measured. It is necessary to use a conceptual framework to specify the relevant phenomena encompassed by the concept, the relations among them, and the identification of meaningful dimensions and categories for measurement (9). It is important that assessments used in a profession fit with practice models and their theoretical foundations. The conceptual models of measurement constructs included in the PEDI and models for practice will therefore be described. These include a disablement framework in accordance with the ICIDH (10), a developmental framework, and a contextual framework. The measurement construct is built on capability in discrete functional skills, the performance of functional activities in response to the environment, and participation in social, family and personal roles (4).

**Figure 1.** Conceptual Model of Measurement Constructs Included in the PEDI



From *Infants and Young Children*. Vol.4:4, p.14. Forsberg H, Hirschfeld H (eds). Movement Disorders in Children, *Med Sport Sci* Basel: Karger, 1992. Printed with permission from Karger.

### ***1.3.1 Disablement Frameworks: International Classification of Impairments, Disabilities and Handicaps (ICIDH), The International Classification of Functioning, Disability and Health (ICF), and the ICF-Children.***

The PEDI was developed in accordance with the World Health Organization's (WHO) International Classification of Impairments, Disabilities and Handicaps (ICIDH) (10) and intends to measure the dimension of disability and handicap related to children's activity performance in their everyday environment. The revised version, ICF – International Classification of Functioning, Disability and Health (11), is a multi-dimensional model classifying functioning and disability related to health conditions, and focuses on components of health rather than consequences of disease. The ICF can be used as a reference for comparison, to which health-status measures can be linked. The classification provides information about the coverage of the breadth and precision of specific concepts. In the ICF, 'functioning' describes body functions, activities and participation. 'Disability' describes impairments, activity limitations or participation restrictions. Functioning and disability are classified as a. Body Functions and Structures and b. Activities and Participation. Contextual factors are seen as influencing health conditions. Activity limitations are problems that an individual has in carrying out a task. Participation is defined as involvement in a life situation. Traditionally, services for children with disabilities have focused on intervention related to impairments of body functions and structures rather than on interventions specifically related to functioning in the dimension of activities and participation. Most outcome measures have thus been developed to measure change in body functions and structures. Few instruments have been developed to measure the dimensions of functioning related to activity, participation and contextual factors. Functional classification can be used to investigate the positive aspects of function within the same framework as well as identifying areas of concerns and needs. This approach encourages a balanced view of children in terms of their



assets and special needs (12), and is useful for encouraging interventions that improve the child's level of functioning.

Bjorbækmo (13) linked the items in the translated Norwegian PEDI to the ICIDH classification. It was found that 96% of the items within self-care were classified as Activity and Participation components and 4% as Body Functions. All the items within mobility were classified as Activity and Participation components. Eighty-three percent of the social function items were classified as Activity and Participation components and 17% as Body Functions. Østensjø et al. (14) analyzed the content and concepts of the PEDI related to the ICF. It was found that the conceptual basis of the PEDI scales to a large extent matched the ICF concepts of activity, participation and environment, and that the PEDI is primarily a measure of activity and participation.

In 2004 a child and youth version of the ICF became available (15). This version is based on developmental theory and recommendations of experts on children with disability. The revision identified several areas for consideration. These included the need to reflect the role of development and age factors, the need to incorporate learning and behavior relevant to childhood and developmental problems, and the need to include environments that are especially relevant for children and youths such as school and home (16). The PEDI was developed in accordance with the old version of the ICIDH-2, but the recently developed ICF-Children fits even better with the original developmental perspective in the measurement construction of the PEDI.

### ***1.3.2 Developmental framework***

Requirements for pediatric functional outcome measures are a developmental pattern and a timetable for achievements of competencies. It is important that the measurement discriminates between normal and delayed functional performance. The assessment needs therefore to be based on data from a sample of typically developed children that allow

comparison of a child's functional performance with what is expected at her or his level of development. The information provided in the PEDI by the normative sample and the developmental framework built into the Functional Skills and Caregiver Assistance Scales enable the user to assess a child's functional status against a standard for what is typically seen at that age (4,9,17).

Standardized developmental milestone inventories include norms that may be less relevant for children with disabilities. Meaningful units of functional capability that are relevant for children with disabilities were selected in the final scaling of the PEDI, as was developmental information about the order of accomplishment and age-relevant expectations of the units (9). The PEDI is designed as a discriminative, descriptive and evaluative tool for functional ability among children with disabilities. Its purpose is to detect whether a deficit or delay exists in children with respect to functional skill development and, if so, the extent and content area of the delay or deficit (4).

### ***1.3.3 Contextual framework***

The physical, social and psychological environments in which children live influence their functioning. When assessing the functional status of children, it is important to recognize the roles of environmental factors as ways to provide support and intervention for children and youths (16). Children's functional activities usually take place under the supervision of others and in environments controlled by adults. Joint management of functional tasks by adults and children is usually the normative pattern, and children's functional performance is related to what their social and physical environment affords (9).

Children are influenced by different social and cultural relationships, which they themselves also influence (18). Negative attitudes, prejudices and myths about disability prevent participation, as do physical barriers. If society were designed in a less disabling way (universal design, inclusive attitudes), there would be fewer people with a disability (19).

Conceptualization of the measurement of function needs to incorporate a description of the participation of other people and of the physical environment facilitating (or hindering) function (9,20). The PEDI assesses the individual child in the context of its own environment while interacting with caregivers and other children as the unit of analysis.

The PEDI has been developed in the U.S.A., a society with living conditions similar to those in Norway. Therefore it might be expected that differences related to the development of American and Norwegian children would be only small. However, differences in child-rearing practices, and social and cultural expectations related to children's development of functional skills become very obvious when an assessment such as the PEDI is applied in a cultural context other than the U.S.A. There are differences in the cultural and social definition's of expectations related to what is developmentally appropriate behavior given the child's age. Such differences are also reflected in the selection of what is perceived to be relevant tasks for children at certain ages. Therefore, it was important to investigate the cultural validity of the PEDI in Norway.

#### ***1.3.4 Models of practice used by occupational therapists***

The PEDI is a multidisciplinary tool which is highly appreciated in pediatric occupational therapy practice judging by its widespread use. It is important that assessments used in occupational therapy fits with practice models and their theoretical foundations. A model of practice provides therapists with guidelines and specific methods for intervention (21). Several models are used in occupational therapy practice. In the mid-1990s a new generation of models evolved, called person-environment-occupational performance (PEO) models (22), which were based on dynamic system theory. Common values and beliefs shared by these models are that occupation is an essential part of human life, contributing to health and well-being. Individuals are valued as unique and important, their perceptions and wishes are respected, and their subjective experience is considered to be of fundamental importance (23).

PEO models include the Human Occupations Model (24), the Model of Human Occupation (25), the Canadian Model of Occupational Performance (26), the Occupational Therapy Intervention Process Model (27,28), and the Occupational Performance Model (Australia) (29).

An occupation-based assessment and intervention focuses on the person's own goals related to occupational performance rather than the underlying impairment. A top-down approach is advocated, meaning that the first steps in an assessment procedure should start with investigating the client's occupational performance (30). Moreover, a top-down methodology often uses a task-oriented approach. In clinical practice the use of the PEDI fits well with occupational therapy models, both as an assessment and as a framework for treatment planning and intervention (9), which can explain its widespread use within occupational therapy.

## **1.4 Development of ADL skills**

### ***1.4.1 Definitions***

*Activities of daily living* (ADL) include how take care of one's body, such as toilet hygiene, bowel and bladder management, bathing and showering, personal hygiene and grooming, eating and feeding, dressing, functional mobility, and sleep and rest.

### ***1.4.2 Different perspectives of learning ADL skills***

How do typically developing children learn ADL? In what way can we use the evidence gained from typically developing children in relation to children with a disability? The knowledge related to these questions has its origin in a variety of scientific disciplines, and can be described from a socio-cultural, cognitive and motor-learning perspective. Available evidence is based mostly on how typically developing children learn ADL skills, and there is limited knowledge of how children with disabilities learn the same skills. When the PEDI is used, these perspectives are operationalized into practice.

### ***1.4.3 A socio-cultural perspective on learning***

The social and cultural environment influences the learning of ADL skills; it is a social phenomenon. Children learn through interacting with others in the environment, and knowledge is constructed through interaction in practical activities. Children also learn by observing the behavior of others (31,32). Demonstrations are often used when teaching practical skills in daily life, whereby the child decides to perform the behavior depending on the situation and consequences. The different questions in the PEDI are answered by the child in its own environment. Therefore it is important that the PEDI items are in accordance with the socio-cultural aspects of where the PEDI is used, i.e. the assessment should be culturally validated.

According to Vygotsky (33) it is the culture in which the child lives that decides what and how the child learns about the world. Learning is often adapted to the developmental level at which the children themselves perform skills and solve problems. Thought and language are seen as a simultaneous process, and cognitive development is seen as a gradual internalization of concepts and relationships encountered through socialization. Vygotsky introduced the

concept of a zone of proximal development. He described this as “the distance between the actual developmental level as determined by independent problem-solving and the level of potential development”, p. 86 (33).

The focus on learning efforts should be concentrated on this zone of proximal development as this reflects the learning potential of the child. The information generated from a Rasch measurement model analysis is particularly useful from this perspective as Rasch analysis organizes items in an assessment in a continuum from easy to more difficult (34). As the PEDI is based on the Rasch measurement model, it can provide guidelines indicating the next item to be learned in terms of increased difficulty, thereby providing a zone for areas of potential development related to the child’s ability. This provides a plan, in terms of development, for intervention and guidance concerning the next step in learning and treatment for children with typical and non-typical development.

#### ***1.4.4 Cognitive perspective on learning***

A cognitive perspective on ADL can broaden the understanding of how children with typical or non-typical development learn skills. It teaches us something about how children process information and construct knowledge for successful performance of ADL tasks.

A cognitive perspective on learning concerns how information is received, chosen, processed, interpreted and stored in the brain. New information is chosen and interpreted in relation to previous experiences, and the individuals are seen as constructing their own knowledge. Most cognitive perspectives emphasize context, since meaning always has to be understood in a context. This is in accordance with the PEDI’s conceptual framework for assessing the child in its natural environment. According to Piaget (35), children construct their own knowledge. Two tendencies are inherited: the tendency to organize (combine, order, recombine, and reorganize behavior in structures and categories) and to adapt to the environment. In the search to adapt to the environment there is an interpretation of new

experiences in relation to the existing structures of knowledge. Two different processes occur in this adaptation. One, *assimilation*, is when schemes are used to understand what occurs. The other, *accommodation*, is when new experiences do not fit with the existing knowledge structures, experiences can either be rejected as wrong, or the knowledge structure has to be changed. In this view, a child continually modifies older, more primitive behaviors for effective motor responses and acquires new skills.

Perceptual motor skills and intellectual skills are closely related to development. A child organizes experiences into mental schemes (concepts) through mental operations (35). The PEDI assesses self-care, mobility and social function, which incorporate aspects of both cognitive and motor functioning. The items are organized into hierarchies of difficulty in the PEDI which fit with the concepts of assimilation and accommodation. The acquisition of new skill is based on mastering previous easier tasks.

#### ***1.4.5 A motor-learning perspective***

Most ADL skills contain a large motor component, and perspectives on motor learning give scientific evidence and general guidelines for intervention (36). There are several theories related to motor learning, which is a synthesis of motor control, motor development and cognition. The motor-learning concept has its origin in Piaget's explanation of cognitive learning, which was developed into the theory of motor learning by Schmidt (37). All theories emphasize the importance of the person being active in the learning and the interaction between the person, occupation and environment.

*Motor performance* is the observable attempt of a person to produce a voluntary action, i.e. the doing. In contrast, *motor learning* refers to internal processes that determine the person's capability to produce motor tasks (38).

Learning of skills can be divided into three different stages:

In the *verbal-cognitive stage* learners get a general idea of the task, often talk to themselves about what they are going to do, and think of strategies that might work. Instructions, demonstrations, and verbal and visual information are beneficial in this stage. Early learning is characterized by the person's attempts to get an idea of the task (39) or understand the pattern of coordination (40). The person has to engage in considerable problem-solving involving both verbal and cognitive processes related to the activity.

In the *motor stage* learners have solved most of the strategic and cognitive problems, and have achieved a general idea of what the movement is. They refine the skill by organizing effective motor patterns (39,41,42). Self-talk is less frequent, and performers begin to monitor their own feedback and detect errors. Instructional feedback becomes less important. When provided, it needs to be precise and target aspects of movement the learner is attempting to refine. Repeated motor performance increases motor learning (43-46). Refinement of movements is different for closed and opened skills depending on whether the movement can be planned in advance or has to be adapted to a changing environment. Learners of open skills benefit most by practicing their movements under diverse sets of environmental conditions.

In the *autonomous stage* the skill is performed almost automatically and is developed into motor programs that can be used to control actions for longer periods (42).

Children often learn ADL skills through taking part in an activity and gradually increasing their participation. It often takes several years to learn a skill, and the prerequisite for doing this is often that children are allowed to take a more and more active part in the skill before being independent. When tasks are practiced at times and places at which they naturally occur, they more quickly become a part of the child's behavior (47).

Random practice usually produces better learning than blocked conditions (a practice sequence in which individuals repeatedly rehearse the same task). In random practice the environmental conditions vary, allowing the child to solve a slightly different movement



problem every time (48). Superior learning is found to occur when practice occurs during random, rather than blocked, conditions in everyday instructional settings (49-53) and in rehabilitation environments (54). A variable practice schedule is advantageous when skills must be adjusted. However, constant practice enhances the performance of motor programs when exact reproduction of the movement is necessary (46).

Instructional feedback can serve as a source of motivation if it is given in a correct way. Feedback may be presented more frequently early in learning but should then be reduced as learners become more skilled in task performance. Instantaneous feedback degrades learning, probably because it interferes with learners' intrinsic feedback processing and error-detecting abilities (55). When applying this to children with disabilities, it is essential to work on functional tasks rather than on movement patterns. It is assumed that patients learn by actively solving problems inherent to a functional task rather than repetitively practicing normal patterns of movement (56).

Research validating theories of motor learning is mostly performed in relation to people without a disability, but a growing number of studies are related to motor learning and neurological rehabilitation. When motor-learning theories are used for children with disabilities, there is an assumption that these children have the same learning requirements as children without a disability.

#### ***1.4.6 Contextual perspective of learning***

The environment's attitudes, as well as physical factors in the environment, can facilitate or hinder functioning for children with disabilities. Contextual factors influence the development of ADL skills and need to be considered during assessment and treatment planning in children with disabilities. Few studies have investigated the degree of influence of social, cultural and personal factors related to the development of ADL skills.

### *Domestic life*

Domestic life is about carrying out domestic and everyday actions and tasks. Areas of domestic life include caring for one's belongings and space, food, clothing and other necessities, caring for personal and other household objects, and assisting others (15). Family and other caregivers and peers provide encouragement and support in those situations. Family expectations, roles, temporal demands and routines for managing daily life influence the child's development of skills, as does the family's size and socioeconomic status (57).

### *Support and relationships*

People that provide practical physical or emotional support, nurturing, protection, assistance and relationships to the child, in the home, kindergarten or at play will influence the development of ADL skills. Adequate support in these functions increases a child's control over the home and school environment, and is related to self-esteem and feelings of efficacy (2), but too much assistance has the opposite effect. Learned helplessness can be a consequence if children with disabilities get too much help. If children do not participate in ADL skills, they learn that they are unable to perform these activities (58,59). Autonomy is related to the person's own right to decide. Children with a disability need to learn how to be autonomous in everyday activities, even if they are physically unable to perform these activities.

The social environment consists of community life, school life, recreation and leisure life, religion and spirituality. Social factors consist of patterns for social interaction in organized societies and social groups, which are based on common interest, values, attitudes and beliefs (26).

### *Attitudes*

Attitudes are the observable consequences of customs, practices, ideologies, values, norms, factual beliefs and religious beliefs (15), and are often referred to as cultural values. Cultures determine the appropriate time to learn a skill, and influence the values and habits of families.

Gesell and Ilg (60) viewed development of ADL skills as a combination of cultural conformance, and expectations of home and preschool. As unique individuals living in certain contexts, children learn these activities at varying rates, and experience occasional regression and unpredictable behaviors as they are influenced by the attitudes surrounding them. Routines for feeding, grooming, dressing, going to bed and carrying out household tasks vary among cultural groups (61-63).

#### *Personal factors*

Interest, self-confidence, motivation and the perseverance of the child influence the timing for when a child masters ADL skills (2,57).

#### *Natural environment and human changes to environment*

Physical factors are natural and human-created environments; consisting of buildings, roads, parks, transportation, and climate (26). The physical environment in the home and surroundings influences the development of ADL skills. Adequate size and type of equipment (for example eating utensils, child's sink, step stool, potty, shower or bathtub, equipment in playground) obstruct or enhance activity and participation.

In the PEDI, the assessment of the child is related to the performance of ADL skills in the child's environment. Contextual factors such as domestic life, support and relationships, and attitudes are indirectly measured in the capability and caregiver assistance scale, whereas the natural environment and changes to environment are measured through the modification scale.

#### ***1.4.7 Development of ADL skills in children with disabilities***

Children with disabilities often have a delayed development of ADL skills. Østensjø has investigated functioning and disability in young children with cerebral palsy (CP). Substantial limitations were found in capacity and performance of everyday activities related to age

expectations in children of all severity levels of CP. These children differed to a great extent from the normative sample of the PEDI (64). Several factors influence the development of ADL skills. In Østensjø's study, independence in everyday activities was best predicted by the child's ability to perform gross motor tasks, and age and the presence of learning difficulties were additional factors. Severity of gross motor limitations was a strong predictor of mobility, self-care, and social function performance (64,65). The acquisition of self-care skills in childhood is intricately involved with the development of motor skill, particularly of the hands (2). Children with disabilities often have difficulties with skilled, manipulatory activities (66), and the degree of disability in learning and performing everyday activities varies with the type and degree of impairment.

There is limited knowledge of how children with disabilities develop ADL skills, and it is often assumed that they learn in the same way as other children. Available evidence about how typically developing children learn can be used, but has to be individualized in accordance with each child's special needs. Learning sessions need to be carefully planned, using a socio-cultural, cognitive, motor learning as well as a contextual perspective.

A prerequisite when planning an ADL intervention is careful analysis of the child's ability and the demands of the activity. The level of difficulty of the activity needs to match the child's ability (i.e. the child's proximal zone of development). The relationship between the level of difficulty of different ADL tasks and the individual child's ability level can be reflected by using the PEDI item maps p. 249-250 (4). The item maps provided in the PEDI, give guidelines concerning which ADL tasks represent the next level of difficulty related to activities within the self-care, mobility and social function domain. This use of the PEDI is valuable because the item maps provide an overview of the development of ADL skills in a clear, visual and unique way.

Østensjø found that modifications for mobility, self-care and social function facilitated both the child's functional independence and lightened the caregiver burden (67). Environmental modifications need to be given equal priority as other interventions in the planning of treatment (68). Task-oriented and activity-focused interventions are suggested in accordance with current understanding of motor control and motor learning for children with neurological disorders. Goals related to activity and participation are addressed first, and thereafter components are dealt with that are supposed to limit and facilitate these outcomes (56).

## **1.5 Assessment of function and skills**

### ***1.5.1 Assessment of function and ADL skills used in Occupational Therapy Practice for children***

When a measure is selected, it is important to know what one wants to assess, and whether the instrument assesses the client's needs. Several measures related to ADL skills are used in Norway, and possible choices will be described. All about Outcomes (69) is an educational CD-ROM program to help evaluate and choose pediatric outcome measures. All about Outcomes was used to identify possible standardized and individualized measures concerning ADL. Instruments were selected if they measured activity and participation, and had a focus on functional skills in self-care, mobility and social function. A further criterion for selection was that instruments could be applied to developmental and neurological disorders in children aged 1-12 years old.

The following measures were found: Activities Scale for Kids, Battelle Developmental Inventory, Canadian Occupational Performance Measure, Goal Attainment Scaling, Klein-Bell ADL Scale, Pediatric Evaluation of Disability Inventory, Toddler and Infant Motor Evaluation, Vineland Adaptive Behavioral Scales Revised, and WeeFIM. Key clinicians in

pediatric services all over Norway were contacted, and the following measures of function and skills were found to be used by occupational therapists in Norway:

*The Assessment of Motor and Process Skills (AMPS)* is an observational assessment used to measure the quality of a person's performance and motor process on goal-directed tasks of domestic and personal activities of daily living. It is a standardized measure used for evaluative purposes, and selected items in the assessment have age norms (70). The advantage of the AMPS is that it is an observational measure of a child's actual ability. The AMPS does not give a systematic investigation of whether the child manages specific tasks of self-care, mobility and social function, but investigates the motor and process skills in general, and their impact on performance.

*The Canadian Occupational Performance Measure (COPM)* (71) is an interview tool designed to aid patients and clinicians in setting goals, planning interventions, and evaluating change (69,72). The COPM enables the child or caregiver to identify problems in occupational performance areas (self-care, productivity, leisure) that they consider important. The COPM is a patient-specific measure in which the problem areas are measured by the individual patient, and the items pools are individualized. The instrument can identify many child-unique problems that are not assessed with existing instruments (73).

*The Goal Attainment Scale (GAS)* (74) measures attributes when no standardized measure is available, and provides clear goals for intervention. The GAS is an individualized instrument, like the COPM.

*The Toddler and Infant Motor Evaluation (TIME)* (75) is a standardized diagnostic assessment tool designed to measure neuromotor changes in children with atypical neuromotor development. It is used with children aged 3.5 years or younger.

*The Vineland Adaptive Behavior Scale (VABS)* (76) is a standardized assessment, designed to evaluate communication, daily living, socialization and motor skills from 0-18

years. The VABS is used in Norway, but has not been validated for a Norwegian population.

As the development of the PEDI is based on VABS, many items are similar.

*The Functional Independence Measure for children (WeeFIM) (77)* assesses the functional outcomes in adolescents and children with acquired or congenital disabilities. The WeeFim was designed to document the severity of disability and need for assistance in children functioning within the developmental level of 6 months to 7 years in the area of self-care, mobility, and cognition. The assessment focuses on functional abilities and level of assistance required. WeeFIM is not translated into Norwegian.

The PEDI systematically investigates self-care, mobility and social function, providing an age-norm for a child's status, and the measure can be used to evaluate change. The instrument assesses the child in interaction with the environment, and is sensitive to modifications. If modifications result in an increase in the child's functioning, an increase in score reflects this type of intervention. Results from the assessment can be used to find the child's zone of proximal development and give recommendations for treatment.

### ***1.5.2 The purpose of a test***

The most important question concerning choosing and using a test is what is required, or desired, to be measured. Then, the appropriate measures should be selected (78,79). A test can be

1. *Descriptive*, describing status, or *diagnostic*, with the purpose of diagnosing the extent of the condition. These tests are often developmental and norm-referenced.
2. *Evaluative*, assessing change over time. These tests are often criterion-referenced.
3. *Predictive*, forecasting outcome (80).

Identifying the purpose of an assessment is important because a measure that is suitable for one purpose may not necessarily be suitable for others. The PEDI is descriptive and evaluative, and is both norm-referenced and criterion-referenced (81,82).

### ***1.5.3 Psychometric properties***

The PEDI is one of the most extensively investigated assessments for children with disabilities in respect of the psychometric properties of the instrument. This dissertation is related to the psychometric properties of the PEDI in the Norwegian culture. To understand the background of this research, there is a need for a general understanding of the meaning of the different concepts of validity and reliability used in psychometrics.

#### *Validity*

Validity is the degree to which evidence and theory support the interpretations of test scores in the proposed uses of a test. Given this definition, validity is influenced by the purpose and the construct of a measure, the item content and the rationale for the item selection. Validity may be the most important aspect of an instrument (80,83). Validation is the process through which the validity of the proposed interpretation of the test scores is investigated. Cross-validation is a procedure in which a scoring system for predicting performance, derived from one sample, is applied to a second sample in order to investigate the stability of prediction of the scoring system (80).

Validity as a concept refers to the degree to which all the accumulated evidence supports the intended interpretation of test scores for the proposed purpose. In the 1999 Standards for Educational and Psychological Testing of the American Research Association, it is recommended that the traditional nomenclature and the way of reporting validity by listing types of validity, such as content, construct, convergent validity etc., should be changed.



Instead the recommendation is to use the concepts of validity related to the sources of evidence (80). For example, instead of reporting “content validity”, this kind of validity is referred to as “evidence-based on test content.” A test can be evidence-based with respect to test content, response processes, internal structure, and relations to other variables.

*Evidence based on test content:* Evidence of validity can be obtained from an analysis of the relationship between a test’s content and the construct it is intended to measure. Test content refers to themes, wording, tasks, questions, format of items, as well as guidelines for procedures related to administration and scoring. Evidence-based content can include logical or empirical analyses of the test content, and analyses of representativeness and relevance to the proposed interpretation of scores.

*Evidence based on response processes:* Analyses of the response processes of test takers can provide evidence concerning the fit between the construct and the performance or response engaged in by the examinee. Evidence of response processes can contribute to questions about differences in meaning and interpretation of test scores across relevant subgroups of examinees. It can also include empirical studies of how observers record and evaluate data and the appropriateness of these processes to the intended interpretation. Are the items relevant to the targeted population?

*Evidence based on internal structure:* Analyses of the internal structure of a test can indicate the degree to which the relationships among test items conform to the construct of the test.

*Evidence based on relations to other variables:* Analyses of the relationship of test scores to variables external to the test, such as convergent and discriminant evidence and test-criterion relationships (80).

*External validity* reflects the degree to which the results may be generalized beyond the study population or situations (84). The relationship between the traditional and newly recommended nomenclature concerning validity was described by Kottorp (85), see Table III.

**Table III.** Comparison of classical and current validity concepts

Classical validity types	Current sources of validity evidence
Content validity	Validity based on test content
Criterion-related validity	Validity evidence based on relation to other variables
Construct validity	Validity evidence based on internal structure
Not specified	Validity evidence based on response process

From: *Occupation-based evaluation and intervention. Validity of the Assessment of Motor and Process Skills When Used with Persons with Mental Retardation* p. 21 Kottorp A. Umeå University Medical Dissertations, 2003.

### *Reliability*

Reliability refers to the consistency of measurements when testing procedures are repeated on a population of individuals or groups. Agreement, precision and consistency in measurement are always desirable, and are evaluated in different forms in reliability studies. Walter, Eliasziw, and Donner (86) give guidelines for sample sizes of raters and subjects in reliability designs. When using PEDI, knowledge about the reliability of the measures is especially important related to the consistency of scores across different measurement occasions and between different examiners, as well as the agreement between the responses of parents and rehabilitation team members.

*Inter-rater reliability* is the extent of differences produced by different raters, whereas *intra-rater reliability* refers to the extent of differences produced when used by the same rater over time. *Test-retest reliability* is the stability of a measure over time; the rater administers the test on two occasions to the same subjects using a time interval during which

change is not expected to have occurred, and correlates the two scores (79). *Inter-response reliability* is the stability of the instrument when two different respondents are assessed by the same rater. *Internal consistency* refers to the homogeneity of a measure in terms of how the items of the test group together into units. This is often tested by examining the relationship between different halves of the instrument by using a statistic called Cronbach's alpha (84).

The hypothetical difference between an examinee's being examined by any particular measurement and the examinee's true score for the procedure is called measurement error. The Standard Error of Measurement (SEM) is a function of the test's reliability, and is used in the PEDI. The SEM can be used to calculate a confidence interval around an observed score within which the true score would lie with 95% probability. Approximately 95% of test scores are expected to fall within plus or minus two standard errors (4,84,87). The SEM is particularly clinically important for interpreting individual's changes over time. It is important to consider that a child's scores are estimates influenced by many factors that are unrelated to treatment factors, including the reliability of the measure. Using the SEM in a clinical setting gives information related to the magnitude of the change in the child's ability, or whether the change might be due to measurement imprecision. The finding in Study III in respect of the reliability of the Norwegian version of the PEDI illustrates excellent reliability with a small variation in scores due to measurement imprecision.

#### *Intraclass Correlation Coefficient (ICC)*

Rater reliability is usually reported with a reliability coefficient. This is an expression of the extent to which raters can distinguish between individuals on different levels of the measured trait (88). To obtain reliability coefficients, the intraclass correlation coefficient (ICC) was calculated. The ICC is computed as the ratio between the variability due to the raters and the total variability of the raters and the individuals. There are several versions of the ICC (84)

related to whether consistency among raters is desired rather than absolute agreement. The type of ICC used depends on whether raters can be considered a fixed or random factor. If raters are classified as fixed, then measuring consistency is investigated. If the interest is in measuring how reliably *any* two raters use a measure, then raters are classified as a random factor. Combining the terminology of Shrout and Fleiss (89) and McGraw and Wong (90), the use of the ICC2 (C,1) reflects a ‘class 2’ in which all patients are evaluated by all raters. This is also called a two-way random model, and was used in Study III. This model is suitable when all subjects are assessed by the same group of raters. Reliability is necessarily related to agreement, and the ICC observes agreement in relation to ranking. A possible problem when calculating the ICC can occur if subjects have the same ability, and are scored the same. Then the ICC does not observe agreement in relation to ranking, as all subjects are similar. The agreement between raters is perfect but reliability is, by definition, zero, which will then be reflected in a low ICC (84).

### **Feasibility**

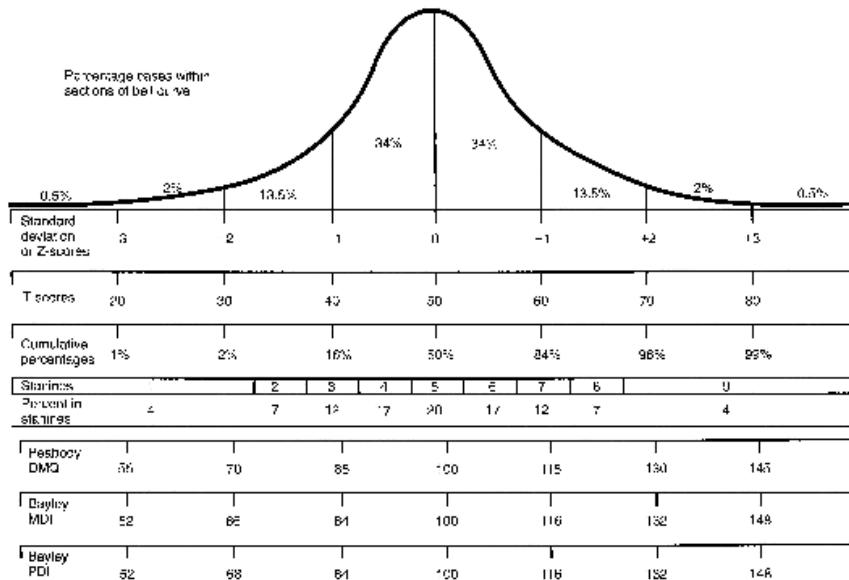
To determine whether an instrument can be used in a clinical setting, feasibility needs to be considered. *Clinical applicability* consists of type of results, type of tasks, administration method, and interpretation of results, and needs to be evaluated. It is important to consider the population(s) used when testing, developing, and applying an instrument. Instruments developed for use with specific client groups defined by diagnosis, age, gender and culture might not be easily adapted for use with other client populations. The reliability and validity of an instrument with one population do not support its validity and reliability in a different population. *Availability and time demands* can be limited by cost, language and whether an instrument is in the public domain. *Acceptability to clients* may influence the willingness to participate in an evaluation. It is important to consider whether the *clients’ perspective* is reflected in the selected measure. The patients’ needs and wants, and the impact of the patients’ environment can be assessed, and what they actually do can be evaluated (79).

## Use of Score

There is a variety of methods for setting scores. However, for more general use, and to be able to compare the results with other instruments, it is sometimes better to transform scores in percentiles to z-scores or T-scores (84). Ordered categories with no well-defined measure of distance between the categories, such as ADL skills, are called *ordinal level data*, and are the most frequently used scores in occupational therapy. If the interval between responses is constant (temperature, height), variables are called *interval level data*. Measures such as means, standard deviations and differences among means can be interpreted by using interval variables, whereas ordinal variables cannot. In ordinal data the degree of difficulty between mastered items is not investigated and considered in the sum score. Ordinal data, therefore, cannot be used to evaluate change (84). The PEDI is designed with Rasch analysis and uses interval level data in the scaled score tables. Thus scores can be used for evaluation purposes. In most measures related to ability, ordinal data are a rating scale. A raw score is obtained and is often used. Raw score's should be interpreted with caution as they are mostly ordinal data. An increase in scores might not reflect an increase in ability; it might just reflect the items being scored (91).

When raw scores are gathered for a normal population, they are normally distributed into a bell-shaped normal distribution curve that describes the distribution of raw scores. *Standard scores* are expressed as the standard deviation of the individual's raw score compared with the mean of the standardization sample's raw score. The mean is commonly 0 with a standard deviation of 1 in a z-score. Different measurements use different scales for standardization. In this way the results can be compared with one another. The PEDI uses a T-score with a mean of 50 instead of 0, and a standard deviation of 10, instead of 1. Fig. 2 illustrates the relationship of the most commonly used test scores to the normal curve and to one another.

**Figure 2** The normal curve and associated standard scores



**FIGURE B-5** The normal curve and associated standard scores.

Reprinted from *Use of Standardized Tests in Pediatric Practice*, Richardson p.255 in *Occupational Therapy for Children*, 5<sup>th</sup> ed., copyright 2005, with permission from Elsevier.

Other types of scores that measurement gives are labeled as *age-equivalent or norm-referenced scores*. This refers to matching the child being tested with how other children at the same age did in a specific sample (standardized sample). *Criterion-referenced scores* reflect an external criterion of functional performance, as opposed to when performance is judged against people (84). The unique psychometric property of the PEDI scales is that the instrument gives both norm-referenced and criterion-reference scores (scaled scores) related to and compared with scores of self and others.

## Rasch Measurement Model (34)

Both the classical true-score theory and item response theory (IRT) were employed in the development of the PEDI. The Rasch model was applied to the development and scale construction in three specific ways: 1. content specification and scale validation, 2. summary scaled score development, and 3. goodness-of-fit analysis between individual child profiles and the overall hierarchical scale intended for each scale. The use of Rasch models facilitates the construction of measurement scales that fit a hypothetical, hierarchical, unidimensional structure. A hierarchical scale defines a continuum of less difficult to more difficult items along a single dimension (4,92).

### 1.5.4 Previous validation of the PEDI

The PEDI is perhaps one of the most widely used and investigated instrument in relation to children with disabilities, and many studies have been conducted based on its validity and reliability. This literature review focuses on the research questions in this dissertation and is limited to research studies investigating validity related to cultural influence on age norms, and reliability (Table I). The literature review gives good evidence for the PEDI's content validity and suggests that the PEDI is a reliable and responsive instrument for evaluating change. Several studies show good responsiveness of the instrument (93-95).

However, studies of cross-cultural validation in different cultures provide evidence of variability related to age norms and the relevance of items in the specific culture.

**Table 1** Literature review of cross-cultural validation of age norms and reliability

Population	Conclusions
VALIDITY	
<i>Evidence-based on test content (cultural validated)</i>	
31 expert reviewers in the USA (96)	Content validity and feasibility were

	supported.
31 expert reviewers in Holland (97)	Topic bicycling added. Confirmation of functional content and feasibility for Dutch PEDI version.
Spanish version (98)	Translated version of the PEDI found valid.
30 expert reviewers in Puerto Rico.	
<i>Cross-Cultural validation: age norms and relevance of items</i>	
Non-disabled children (n=52) (99)	Good correlation with American norms. Pearson's $r$ for functional skills ( $r=0.90-0.98$ ) and caregiver assistance ( $r=0.93-0.99$ ).
Non-disabled children (n=20) (100)	Score profiles for Dutch children not found compatible with American peers.
Children with disabilities (n=22) (101,102)	Qualitative and quantitative data analysis confirmed that differences exist between Puerto Ricans and the norms established in the USA. Different than the US norms related to how and when children perform PEDI activities, with expectations of caregiver concerning later performance of skills. Results pointed to the need to re-standardize normative values.
Children without disabilities (n=22)	
More than 600 Puerto Rican teachers, parents and caregivers of children with and without disabilities.	
Slovenian children without disabilities (n=147)(103)	Statistically significant differences between children in the American and Slovenian samples were found in several domains of Functional Skills and Caregiver Assistance scales in the three age groups investigated. Statistically significant differences between girls and boys in self-care, boys scoring lower than girls.
Dutch children without disability (n=1849) (104)	Six items in the PEDI-NL added. Significant difference between girls and boys in self-care, boys scoring lower than girls. For the self-care and mobility domain, lower sum



score than in the US considered normal in almost all age groups in the Netherlands.

## RELIABILITY AND ERRORS OF MEASUREMENT

Non-disabled children (n=412) (4,105)	Internal consistency coefficients for the three domains range from 0.95-0.99. Inter-interviewer reliability coefficients (ICC) were 0.79-0.98.
Children with disabilities (n=102)	Inter-interviewer ICC was 0.84-0.99. Inter-respondent reliability was high, except for social function domain (ICC=.30).
Children with CP (n=21) (106)	Test-retest with 3-week interval. Inter-rater reliability ICC 0.72-0.87. Intra-rater reliability ICC from >0.80.
Children receiving OT and PT (107)	
Intrarater (test-retest) (n= 23)	ICC ranged from 0.67 to 1.0.
Inter-respondent (n=17)	ICC ranged from 0.18 to 0.94. High level of agreement except for social function. Inconsistent findings were typically not observed in the clinic.
Children with developmental, acquired brain injury and spina bifida (n=20) (108)	Inter-rater reliability ICC from 0.82 to 0.94.
Children with spastic CP (n=115) (8)	Internal consistency (Cronbach's $\alpha$ ) 0.90, PEDI scales excellent internal consistence (all $\alpha$ values 0.98 or more.
Children with disabilities (n=53)(109)	Inter-interviewer reliability was studied after scoring audiotaped interviews by second researcher.
Children without disabilities (n =63)	On a scale level all ICC were above 0.90.
Sample included both groups	Inter-interviewer (n=31) ICC=0.99. Test-retest (n=20) ICC=0.91-0.98. Inter-respondent (n=32) ICC=0.91-0.99.
Children without disabilities (n=63) (104)	Cronbach's alpha self-care $\alpha$ =.89, mobility $\alpha$ =.74, social function $\alpha$ =.87.

## **2 AIMS OF THE THESIS**

The overall objective of the study was to translate the American PEDI into Norwegian and to assess the applicability and validity of the translated version.

The specific objectives were to study whether the Norwegian version of the PEDI was

- functionally equivalent to the American version.
- reliable in relation to inter-rater, intra-responder and intra-rater reliability for children without disabilities between 1.0 and 5.9 years of age in Norway.
- useful according to US normative data for a general Norwegian population.

### **3 MATERIAL AND METHODS**

#### **3.1 Study design**

The sample selection and data collection were done in three studies. The translation of the American version of the PEDI into Norwegian was based on guidelines related to cross-cultural adaptation recommendations for obtaining semantic, idiomatic, experiential and conceptual equivalence in translation using back-translation techniques, committee review, pre-testing techniques and re-examining the weights of scores to the cultural context from Guillemin et al 1993 (110).

Study 1. The Norwegian version of PEDI was translated over several years by a research group comprising 4-5 members (5). In Norwegian there were no words for several of the terms used in the American PEDI (se Table III p. 62, Paper I). To achieve content validity words and phrases had to be changed. Items and words changed were presented in Paper I (111).

Study 2. The next stage in the validation process was a pilot study based on cross-sectional principles, Paper II (112), and rater agreement, Paper III (113), of the Norwegian version of PEDI.

Study 3. Since the results were based on a small number of subjects, a population-based cross-sectional study (Paper IV) was designed to evaluate the applicability of PEDI American normative data to a general Norwegian population (114).

#### **3.2 Translation**

##### *Adaptation procedure*

The translation process (Study I) involved four professionals translating the original version in parallel and independently into Norwegian. Membership of the committee was multi-

disciplinary, and included bilinguals. The translations were discussed until consensus was reached (synthesis of translations). The scoring criteria for capability and performance were perceived as confusing. The guidelines in the PEDI manual define capable as: “capable of performing item in most situations, or item has been previously mastered and functional skills have progressed beyond this level” as equivalent to a score of 1. In the translation this was further defined to “performing the skill more than 50% of the time”.

The Norwegian version was submitted to an independent translator (back translation), which resulted in only minor adjustments being made. Parallel to, and after, the back translation, 10 courses concerning the use of the PEDI were held for multi-disciplinary experienced professionals. Issues of conceptual equivalence were discussed (111).

In Study II applicability and reliability were investigated. The translated version showed excellent agreement in respect of the observations (113). Applicability of the Norwegian version of the PEDI was investigated in a sample of 52 children without a disability. Findings deviated from the American normative reference values, and the result called for a larger study (112). Questions were raised concerning whether the deviations from the American reference values were due to the changed scoring criterion for capability. Therefore, in Study III, the scoring criterion was revised to “1=capability; the child performs the task in most situations or behaviors previously mastered but no longer required or used”. One of the investigators of the PEDI confirmed the translation, and the revised translation of the scoring criteria was used in this study (114).

### **3.3 Subjects**

The participants in Study II, 52 children aged 1 – 5.9 years, were recruited from Nesodden municipality between 1994 and 1998. The participants in Study III were recruited from the

counties of Østfold and Oslo, including children born during 1999 and 2003, and consisted of 176 children aged 1 – 5.9 years from randomly selected kindergartens in Norway.

The age range was chosen because the self-care scale in the PEDI plateaus at approximately 5.5 to 6 years (115), and the mobility scale even earlier. Those with mental or physical disorders, adoptive children or children of two non-ethnic Norwegian parents were excluded.

**Table III.** The distribution of participants in the different studies.

Study	No. of participants	Age in years	Overlap in study groups
I			
II	52	1.0-5.9	Same sample in Paper II and Paper III
II	30*	1.0-5.9	
III	174	1.0-5.9	

\*For detailed information see Table 1 p. 65 in Paper III.

### 3.4 Data collection

For Study II the subjects was selected from 1411 children aged 1.0 – 5.9 years living in Nesodden municipality. They were sorted according to age and postal area code following a registration made by Statistics Norway. Following the list a systematic selection of every 15<sup>th</sup> child was made. Accordingly, parents of these 94 children were sent a letter of invitation to participate in the study. Forty parents agreed to participate, giving a response rate of 44%. An additional 12 children were then included from Oslo and Nordland by convenient sampling to increase the number of participants in the study necessary for the statistical power for inferences. These convenient samples were collected from the health workers who were participating in a course at a local hospital in Nordland, n=6, and Oslo, n=6. In total we had 52 children. Forty-eight mothers and four fathers were interviewed. Parents were asked

whether their children had any mental or physical disorders, and children with such disorders were excluded from the sample. Participants for Paper II and III were from study II.

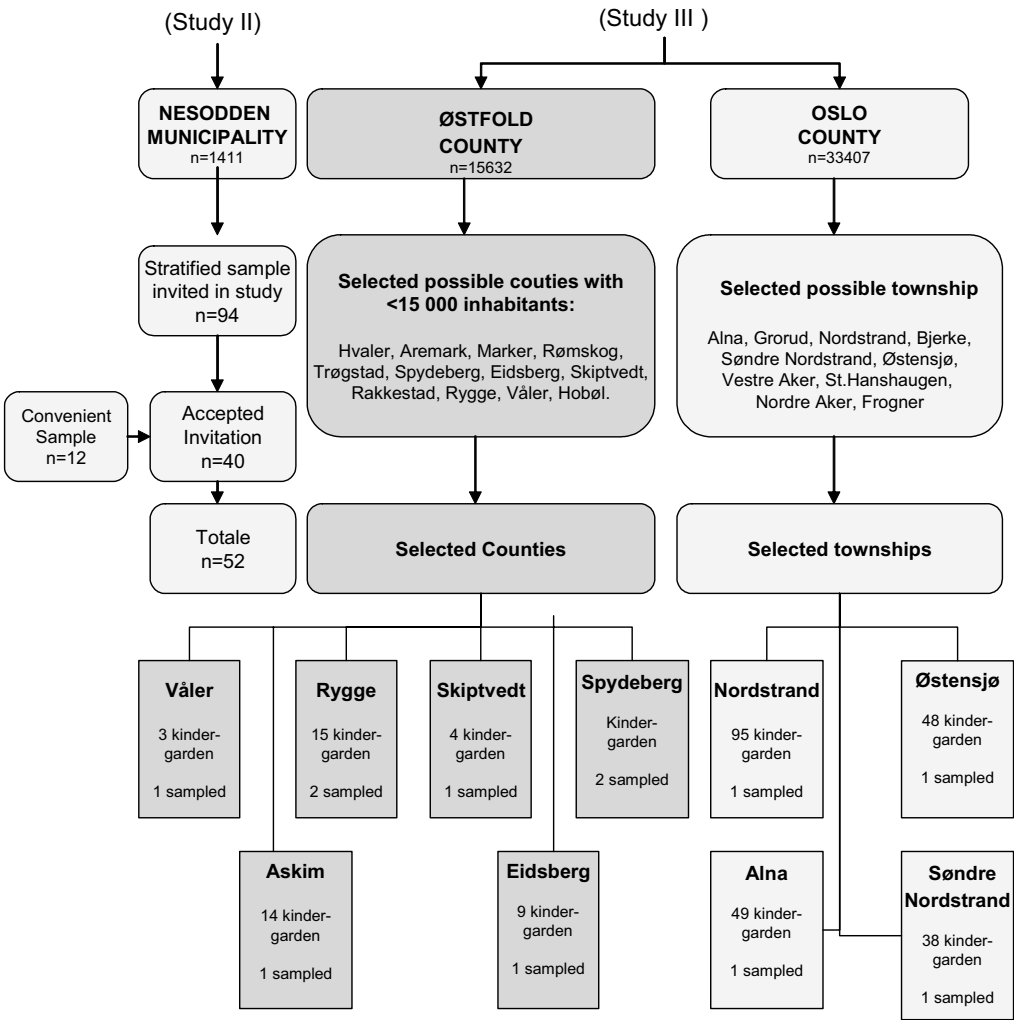
In the population-based Study III, the selection was based on a multi-stage sampling procedure. At first 2 out of 19 counties from the districts of Oslo (urban) and Østfold (with mixed municipalities) were selected. Oslo consists of 15 townships with a varying number of kindergartens. Kindergartens in Oslo were only included in this study if they had children in the age range 1 – 5.9 years. To accommodate the socioeconomic differences, less and more affluent townships were stratified. Five kindergartens were selected from the less affluent and 3 from the more affluent areas in Oslo following a simple random procedure. From the available kindergartens listed on the township's internet pages, four kindergartens were randomly selected to participate. All parents from the selected kindergartens were invited to participate.

In Østfold county we primarily selected communities with less than 15,000 inhabitants in order to reflect the general size of municipalities in Norway. Following this procedure 14 municipalities were selected, of which 6 were randomly selected and included in this study. Nine kindergartens were randomly selected from the 6 municipalities, and 8 participated.

Following the procedure, a total of 478 children in the selected kindergartens were contacted, and 176 participated in the study. Two children were excluded because of mental or physical disorders. Previous studies have shown that adopted children may have a developmental functional delay (116) and thus were excluded from the study. Children of two foreign parents were also excluded from the sample, as functional performance can be related to culture (101,103,117). Therefore we have excluded children from different cultural background other than ethnic Norwegian. As the sample size was rather small, it did not permit stratified analysis with necessary statistical power. During interviews 138 mothers and 8 fathers participated on their own. There were 26 couples and 2 grandmothers. The mean age

of the mothers was 34 years (range 24-45) and the mean age of fathers was 35 years (range 30-46). The sample in both studies corresponded well with a general Norwegian population, with a slightly higher proportion of mothers with more than 16 years of education. All interviews were conducted by the author and lasted approximately 60 minutes. Parents were interviewed in accordance with their preferences, either in the kindergarten, at home, or at their workplace. Each interview started with the interviewer reading the scoring criteria and clarifying questions.

**Figure 3** Sample selection



### **3.5 Data analyses**

In Paper I, terminologies and phrases used in the original version of PEDI were systematically analyzed to identify comparable Norwegian terminologies with content equivalence.

Guidelines from Guillemin et al (110) were used. We developed new terminologies that were similar to the American terminologies where none were available. The chosen translations were described and compared with the original terminology. Consensus meetings were held six to seven times a year throughout the translation procedure, within the research group and with representatives from different professions.

In Papers II and IV the six PEDI subscales were separately summed up and described with mean values, standard deviations and range distributed from age intervals of six months from 1.0 to 5.9 years. For each item and within each age group, the distribution of the percentage of children managing the tasks was computed and compared with normative values. To compare the mean of 50 of the American age norms and the observed scores, one sample *t*-test was used. Independent sample *t*-tests were used to compare the results from subgroups such as boys and girls. In Study IV, we also applied ANOVA tests to compare results from subgroups such as mother's education and degree of urban residencies (variables with three or more categories).

The statistical analyses were conducted using the Statistical Package for Social Science. Version 9.0 and 12.0 software package were used for data registration and statistical analysis. A *p*-value less than 0.05 was considered statistically significant.

The questions asked about descriptive statistics for continuous variables were given as mean values with standard deviations (SD). For categorical variables, frequency counts were calculated and displayed in tables when appropriate in Papers II, III, and IV.



In Paper III summary scores (raw scores) were obtained by adding the scorings within each domain. The means and standard deviations (SD) were calculated. Differences in scorings between different interviews were investigated by descriptive statistics (118). The reliability was quantified by Intraclass Correlation Coefficient (ICC). The ICCs were computed for consistency of average measures in two-way random models. Plots of the mean scores for each content area obtained in different interviews were included to illustrate the discrepancy in content areas between interviews.

### **3.6 Ethics**

All studies in this thesis related to people were approved by the Regional Ethical Committee for Medical Research and the Data Inspectorate in Norway. Parents were invited to join the study with no obligation. All parents in the kindergarten received a written invitation. To confirm their participation, the parents returned the response form. Verbal information about the purpose of the research was provided to the parents prior to the interview. They were informed that they could withdraw from the study at any stage. Those participating during the autumn of 2004 were not remunerated. Those participating during the spring of 2005 received a children's book as a token of gratitude.

## **4 SUMMARY OF PAPERS – MAIN RESULT**

### **4.1 Translation of a Multi-disciplinary Assessment – Procedures to Achieve Functional Equivalence (Paper I)**

The results confirm the Norwegian version of the PEDI's translational equivalence with the original version. Several items, and words, and one scoring procedure were changed during the consensus process to achieve content, conceptual, semantic and idiomatic equivalence.

The back-translation showed an insignificant deviation from the original American version, and was adjusted accordingly. The chosen translation of words and concepts not available in Norwegian was published and can thus be investigated by the scientific community that does not speak Norwegian.

The scoring criteria for capability and performance were perceived as confusing by parents and health professionals, and were further defined as performing the skill more than 50% of the time. Contextual settings of professional groups in the society at large were taken into consideration, as were linguistic challenges. Rather than selecting an expert-based model, a consumer-based model was chosen, which was based on feedback from the clinicians of different professions who were going to use the instrument in their everyday practice. It was necessary to expand on the translation procedures to ensure the selection of common terminology that would be appropriate for a number of professional groups.

## **4.2 Applicability of the Pediatric Evaluation of Disability Inventory in Norway**

### **(Paper II)**

The majority of items in the Norwegian version of the PEDI was perceived by Norwegian parents to be relevant and applicable in Norwegian culture.

However, the Norwegian sample scored significantly lower than the American reference values for Functional Skills; self-care (mean 39;  $p < 0.001$ ) and mobility (mean 43;  $p < 0.001$ ) and for Caregiver assistance; self-care (mean 43;  $p < 0.001$ ). There was a clear lack of fit for items related to grooming and bathing, involving tooth brushing, washing the body, brushing and parting hair, nose care and buttoning. Toileting and management of bladder and bowel were mastered later than in American reference norms. Transfers on/off chair, toilet, bed and seat-belt management also deviated from the American normative values (112).

### 4.3 Reliability of the Pediatric Evaluation of Disability Inventory (Paper III)

The results confirm that the Norwegian version of the PEDI produces reliable measures. The results indicate that enhanced reliability is secured when the same interviewer interviews the same respondent, as well as when two trained interviewers interview the same respondent ( $r=0.95-0.99$ ). The length of time between interviews was no longer than 21 days as normal development could affect performance. The intra-rater reliability study showed good agreement in all domains, with the exception of Functional skills: self-care, shown in a Bland-Altman plot in Table 4, p 72, (113), in which the parents reported increased function at the second interview in the areas of tooth brushing, hair brushing, hand washing, washing body and face, and fasteners. A systematic difference with a mean difference of -2.00, and a range of difference of -7 to 2, reflects this, although the ICC was 0.99.

Different respondents who know the child from different settings, for example parents and primary caregivers or other professionals, may differ in their understanding of the child's performance ( $r= 0.64-0.74$ ). As not all items in the PEDI were observed by the kindergarten teachers, it was not possible to use the ICC to analyze the data for these domains. Plots of mean scores were used to analyze the difference of agreement between parents and kindergarten teachers' perception of self-care and mobility. Parents tended to score their children higher than kindergarten teachers in the areas of functional use of communication, peer interaction, playing with objects, household chores and community function. Parents also scored higher than kindergarten teachers related to caregiver assistance in the areas of functional expression, joint problem-solving and peer play. The consistency of scores should be reviewed when different respondents are interviewed.

In contrast, kindergarten teachers scored the children higher than the parents did for Functional skills: self-care, in relation to hand washing, fasteners, pants, and toileting tasks. In the caregiver assistance domain of self-care, kindergarten teachers scored lower (giving more

help than parents in dressing and toileting). There was good agreement between parents and kindergarten teachers' perception of mobility, as shown in Table 2, p. 71 (113).

#### **4.4 Cross-cultural validation of the Pediatric Evaluation of Disability Inventory (PEDI) norms in a randomized Norwegian population (Paper IV)**

Although living conditions in Norway seemingly do not differ from the US western style of life, differences were found in normative values. The results showed that the Norwegian sample scored significantly lower than the US reference values for functional skills and caregiver assistance, especially for self-care. Capability and caregiver assistance in the domains of self-care, mobility and social function ranged from a mean of 38.0 to 46.8 against an expected 50. Most items related to grooming and personal hygiene were mastered about one year later by the Norwegian sample, as was buttoning. The most significant difference between the Norwegian and the American sample was found in the use of diapers. The Norwegian sample was continent 12 – 18 months later than the US normative group. The Norwegian children were independent in self-care at a later stage than children in the US, and boys scored significantly lower than girls in self-care. For mobility and social function, the results are of less significance. Indoor and outdoor locomotion skills were mastered earlier in the Norwegian sample. Items related to transfers using arms deviated. Some items related to social functioning (understanding directions, naming things, describing problems/feelings, simple pretend play, simple time concepts) were mastered one year later in the Norwegian samples, whereas items related to getting about a familiar environment and following guidelines in kindergarten matured earlier.

In the previous study of applicability, results also deviated significantly from the US normative values with respect to self-care in functional skills and caregiver assistance (112).

This is partly confirmed in the present study with an even larger deviation in self-care: caregiver assistance (mean 38.0 versus 43.1 in the pilot-study), but the difference was not statistically significant ( $p=0.17$ ). In the domain of mobility, the previous study deviated significantly from the reference values in functional skills, but had good correlation in caregiver assistance. The findings with respect to mobility: functional skills (mean 43.0) were confirmed in the validation study (mean 43.9,  $p=0.21$ ). Furthermore, in this population-based sample, the caregiver assistance mean for mobility was significantly reduced to 46.5 ( $p<0.001$ ). Social function correlated well with the normative reference values in the previous study (mean of 50 for both functional skills and caregiver assistance). However, social function had a significantly lower mean sum score value in the validation study ( $p<0.001$ ) for functional skills (mean 46.6) and caregiver assistance (mean 46.8).

## 5 DISCUSSION

### 5.1 Concepts of Capacity, Capability and Performance

When an assessment is translated into another language, it is necessary to achieve equivalence between the original and translated version of the scale even though some words and concepts do not allow exact translation. Concepts of capacity, capability and performance will be discussed related to the translation of the Norwegian PEDI.

Research into children's development relates to whether the child has the *capacity* to perform a skill or whether the child spontaneously *performs* the skill in its natural environment (119,120). The capacity question is best answered by using tests in a standardized and controlled environment, and it is necessary to observe the child in its natural environment to answer the question of performance. This definition of capacity and performance is also reflected in the ICF, in which capability is not mentioned (11). The PEDI manual states that "capability refers to the performance of tasks in either a standardized or an

ideal situation. It provides knowledge of the child's best performance" (4) p.7. The criteria for capability in the PEDI are scored as: 0=unable, or limited in capability, to perform item in most situations: 1=capable of performing item in most situations, or item has been previously mastered and functional skills have progressed beyond this level.

According to this statement, capability has the same meaning as capacity, whereas the term "in most situations" contradicts this when reflecting performance. Østensjø (14) found that both the PEDI and the ICF use the constructs of capacity and performance, but differ in the operationalization of these constructs. The capability construct of the PEDI differs from the capacity construct of the ICF because the PEDI refers to a natural environment, whereas the ICF refers to a standardized environment. To enhance meaningful clinical interventions related to the daily life of children and their families, there is a need to gain knowledge of what the child can do in its own environment and not in a standardized or ideal situation. Because it often takes several years from the time a child has the capacity to do a skill occasionally until this is performed on an everyday basis in relevant situations, this distinction of capacity and performance is important when assessing a child's functional capability. The concept of what the child *can do in its own environment* is not covered in definitions of capacity and performances included in the ICF.

In the PEDI manual, capability is described as capacity, whereas the addition of "performance of skill in most situations" reflects performance. In the first study on the applicability of the Norwegian version of the PEDI, capability was therefore translated as "performing the skill more than 50% of the time" in an attempt to make the scoring criteria more precise. When the performance of Norwegian children deviated from the US normative values in the first study of the applicability of the Norwegian PEDI, referees commented that the change entailed by the translation of the scoring criteria might be the cause of the deviation. The scoring criteria were then changed to performance in most situations.

However, results in the subsequent study with changed scoring criteria were similar to the original study (112).

According to the PEDI manual, the functional skill scale reflects capability and the caregiver assistance scale reflects performance. The use of “performance in most situations” in the functional skills scale makes the distinction between capability and performance small. This might lead to a feeling among parents and therapists that the same questions are being repeated and that only one of the scales is needed. However, the caregiver assistance scale has more of an independence-related focus for larger performance areas within ADL, whereas the functional skill scale assesses mastery of discrete ADL skills.

Another consequence of not carefully distinguishing between capacity, capability and performance can be that different age norms for mastery of skills are identified, as there is a difference between the age at which a child *can* perform a task and when he/she actually *does* it on an everyday basis. Differences in age norms as presented by various tests can also be related to the use of diverse strategies for presenting the typical normative age or time interval for particular functional skills. Tetzchner (18) gives example of this, referring to Gesell and Armatruda (121), who describe the age when 75% of the children have mastered a skill. In contrast, Holle (122) used the mean for the group she investigated. Piper and Darrah (123) and Haley et al (4) describe when 50% to 90% of the children have mastered the skill. Age norms are also influenced by a large variation in age, sometimes as much as 3 to 4 years, with respect to when children normally master a certain self-care skill (4).

There is a need to construct the measurement of children’s development in accordance with the ICF’s definitions in the future, and to use the same strategy to present a typical normative age for a skill to enable comparison of age norms.

## **5.2 Applicability and cross-cultural validity of the Norwegian PEDI**

The result of Studies II and III showed that within the domain of self-care, items of eating and dressing there were only small deviations from the norm. But hair brushing, tooth brushing, body and face washing, buttoning, zippers, bladder and bowel control and toileting tasks were mastered a year later than the US norm. Are Norwegian children generally delayed? Most probably not. But parents did not perceive early independent mastery of grooming as important. Thus they did not encourage or expect their children to do it themselves. Furthermore, dentists in Norway advise all parents to brush children's teeth until 10 years of age because children are not expected to clean their teeth thoroughly at earlier ages. Tying shoes was also something Norwegian children achieved later than the American sample. Most children in the Norwegian sample had Velcro® straps on their shoes, not shoelaces. These items were thus not relevant for the age groups investigated. The most significant difference between the Norwegian and the US samples was found in the use of diapers. Seventy-five percent of the Norwegian children were continent during daytime at 48 months of age, which is 12 – 18 months later than the US normative group. In Sweden a similar trend was also seen in a recent longitudinal study of bladder control in healthy children, which found that the median age for attaining daytime and night-time dryness was 42 months and 48 months, respectively (124). There may be several reasons for this. Scandinavian cultural values related to toilet training emphasize not stressing the child, and parents reported that they did not provide toilet training before they perceived that the child was 'ready' for this. In some countries, children are not welcome in kindergarten before they have mastered toilet skills, which is not the case in Scandinavia. In a recent survey related to a toilet-training programme and toilet skills in the U.S.A, a cohort of children from 15 to 42 months was studied. The median ages for staying dry during the day were 32.5 months and 35 months, respectively, for



girls and boys (125), which seems to be in accordance with the PEDI US norms (4). Perhaps an earlier start to toilet training in the U.S.A. could explain the finding that the Norwegian children stayed dry about 10 months later than their US peers. However, at 4.5 – 5.0 years old, 90% of both Norwegian and US children stayed dry day and night.

Several other items in the PEDI may be related to toilet training onset. The prolonged use of diapers means that children are most often helped to take off/put on pants, and with zipping and buttoning. Thus the child might not be encouraged to participate in these components of the dressing activities either.

The Norwegian sample had lower results related to transfers not using arms, and in car and tub transfers, and higher results related to indoor and outdoor locomotion. Parents generally commented that they had not paid attention to whether their children used arms or not in transfers, information that the PEDI sought. Transfers in and out of cars were mastered later than the US norms possibly due to car locking, complicated seatbelts, and the fact that many parents drove elevated vans, which mean that children were lifted in and out of car. However, items concerning indoor and outdoor locomotion were mastered earlier in the Norwegian sample, in accordance with Norwegian habits of weekly family hiking.

The Norwegian sample had lower results in items related to simple time concepts, initiating household chores and understanding directions. Concepts of time are not generally taught to children before the second year in school in Norway, and initiating household chores is seldom a focus in Norwegian child-rearing. On the other hand, the Norwegian sample had higher results in items related to getting about familiar environment outside home, and following school guidelines. Many children in Norway live in relatively safe environments, and can move around rather freely with few restrictions.

The sample was well representative of Norwegian children, but scored significantly lower in many items compared with the US norm. Differences in child-rearing practices become

obvious when applying an assessment such as the PEDI to another cultural context than the USA. There are differences in cultural and social definitions of expectations related to what is appropriate developmental behavior given the child's age. Such differences are also reflected in the selection of what is perceived to be relevant tasks for children at certain ages. Consequently, the US age norms are not immediately applicable because of cultural differences.

#### *Comparison with the results from the earlier Norwegian applicability study*

In the applicability study (Paper II) the results from the Norwegian sample deviated significantly from the US normative values with respect to self-care in functional skills and caregiver assistance (112). This trend was confirmed in the randomized population-based study (Paper IV) with an even larger deviation in self-care: caregiver assistance (mean 38.0 versus 43.1 in the pilot-study,  $p=0.17$ ). In the domain of mobility, the applicability study deviated significantly from the reference values in functional skills, but had good correlation in caregiver assistance. The findings regarding mobility: functional skills (mean 43.0) were confirmed in the validation study (mean 43.9,  $p=0.21$ ). Furthermore, in this larger sample, the caregiver assistance mean was significantly reduced to 46.5 ( $p<0.001$ ). Social function correlated well with the normative reference values in the previous study (mean of 50 for both functional skills and caregiver assistance). However, social function had a significantly lower mean sum score value in the larger study ( $p<0.001$ ) for both functional skills (mean 46.6) and caregiver assistance (mean 46.8). Thus, the larger sample in Paper IV confirmed the findings from Paper II and even strengthened the result of deviating norm values.

### 5.3 Reliability of the Norwegian PEDI

The results of the Paper III demonstrate that the Norwegian version of the PEDI produces reliable results. The inter-rater reliability study (n=19) had an excellent ICC ( $r=0.95 - 0.99$ ). The same 30 children were used in the inter-rater, intra-responder and intra-rater reliability study. Of the 30 children, 18 parents were interviewed twice, 6 were interviewed three times, and 6 were interviewed four times (Table 1, p. 65 (113)). Using the same 30 children in all studies may, however, have affected the measurements, as repetitive observations can lead to fatigue (86). Fatigue among respondents may have limited the sample size in the interresponder (n=14) and intra- responder (n=15) study, as a PEDI interview takes 45 – 60 minutes, and some families participated in several interviews. The small sample size can be seen as a limitation of the study. However, other studies investigating the PEDI's reliability (8,107,108) have had a similar sample size, and according to Walter (86) an adequate sample size in a reliability study is n=18. One strength of the design is that it allowed the PEDI's baseline to be examined during several measurements and is a similar design to the way the measure is used in clinical practice.

Few have previously investigated the reliability of the PEDI in a population-based study, and using children without disabilities enabled the investigation of a standard for functional ability.

In the inter-responder study, somewhat lower agreement was found. As not all items in the PEDI were observed by the kindergarten teachers, it was not possible to use the ICC to analyze agreement between parents' and kindergarten teachers' perception of children's self-care and mobility function. Instead, plots of mean scores were used for self-care and mobility items. The results showed that children were rated more capable in relation to toileting and dressing by the kindergarten teachers, who reported that many children chose not to use the toilet for bowel management and thus were quite independent concerning toileting in that

environment. Some parents reported that they preferred to use trousers without buttons in the kindergarten to enhance their child's independence in toileting. These observations are examples of contextual factors influencing performance, when different respondents rate a child in two different environments.

All items of social function were observed in the inter-respondent study, and the ICC could then be used to analyze data for this domain. A different context (other adults, children and a different environment) might affect a child's capability and performance related to social function. Many parents reported that they did not observe their child in interaction with other children, except for siblings, family or children who were familiar to their child. This might be one of several explanations for parents rating their child higher than kindergarten teachers did. Fewer adults might offer help in kindergarten than at home, thus affecting the child's performance. Social functioning was probably more challenging in the kindergarten, which also affected performance scores. The low sample size ( $n=14$ ) and small variation in age (3.2 – 5.4 years), and the resulting similar level of functioning, might have affected the results of the social function domain data, as the ICC observes agreement in relation to ranking. A larger sample and bigger variation in age and ability might have given higher results for the inter-respondent reliability. The ICC results of 0.64 – 0.74 should therefore be interpreted with caution.

The intra-rater reliability study showed good agreement in all domains, with the exception of functional skills: self-care. With repeated interviews, children tended to master more skills on the second, third and fourth occasions. The PEDI interview seem to raise awareness of the child's capability, and parents reported that the initial set of PEDI questions motivated them to focus on functional skills (especially the self-care items). Thus their children increased their skills. Children's capability in self-care tasks is influenced by parents' expectations, and thus seem to improve with repetitive assessments. The PEDI interview per se might have

served as an agent to improve performance. The PEDI is used as an evaluative instrument, and the possible effect of increased ability as a result of merely raising the issue of the child's independence should be considered as a possible reason for change. In this study, the PEDI was found to produce reliable measures for children with typical development, but should also be investigated in a sample of Norwegian children with disabilities.

#### **5.4 Methodological issues related to design and sampling**

Children assessed with the PEDI were measured in a contextual setting in the child's everyday life. It was therefore necessary to investigate whether items in the PEDI reflect expected performance of children in Norway, and whether the items used were perceived as relevant by parents. We chose a population-based design to ensure maximum representativeness under the prevailing conditions of limited resources and time. Possible problems concerning design can be related to sampling, data collection, data analysis, internal and external validity, and whether selection, participation and information bias have influenced the results.

Was the sample in Studies II influenced by individual characteristics or by preference? This question can be referred to as selection bias. Despite employing a systematic selection procedure less than half of the children participated. But those who did participate were not selected, therefore it is less likely the results were influenced by selection bias. In study III the selection is based on a random sampling technique from all eligible children in the specified age group in the specified municipality. Therefore we have reasons to believe that the results from Study II were valid, even in a small sample, which was also confirmed in Study III.

Study III is a population-based randomized study, and selection bias may have occurred because of the selection of only 2 of 19 counties in Norway. The limited number of counties selected was due to financial reasons and time constraints but followed a multi-stage random

sampling procedure to secure the necessary scientific strength for the results. To get valid responses, it was necessary to meet respondents eye to eye, with the possibility of follow-up questions when required. Telephone interviews would probably have given a serious information bias in this population as the interview was extensive. Children were randomly selected from a stratified socio-economic, urban/mixed municipality population and geographical neighborhood. The sample was collected following the design of a population-based randomized procedure, and may be considered representative as Norway has a rather homogenous population.

Did the response rate affect the results of Paper II, III and IV? A low response rate may lead to participation bias. Low response rate in an urbanized study is often considered a typical norm of a busy lifestyle. Previous studies in Oslo with a low response rate, however, uncovered the fact that those who participate did not differ compared with those who did not (126-128). Although the response rate was rather low (43 % in Studies II, and 37% in Study III), the response rate was comparable with other studies conducted in Norway (127,129). In the Dutch standardization, the sample (n=1849) was large but had a response rate of 17%. This reflects the difficulties involved in engaging participants in this kind of study (109) and might induce a bias in relation to participation in the Dutch study.

Janson, using a mailed questionnaire, found in a study of normal development of Norwegian children that the response rate was higher for parents with younger children (127). In Janson's study, it was found that the response rate decreased from 76% at 8 months to 32% at 60 month. However, a low response rate does not automatically imply differences between respondents and non-respondents (130).

The children in all the studies in this thesis had no functional disability. It is not unlikely that parents did not experience any problems or health issues that would be rewarded by participation in this study and therefore did not prioritize participation in their busy schedule

(129,130). With 37% of the parents participating in Study III, it can be viewed as a reasonable response rate as it was not in their interest to participate.

The sample in Studies II and III appeared to correspond well with the general Norwegian population for demographic and socio-economic status, with a slightly higher proportion of mothers having more than 16 years of education. Also in the normative sample in the US for the PEDI, there was an oversampling of families with 4 or more years of college education (131).

Previous studies investigating the cross-cultural validity the PEDI's age norm have not applied strict population-based design to data sampling. However, the standardization sample of the original PEDI was carefully designed to match the demographic characteristics similar to the United States population. No data on response rate were given related to the cross-cultural validation of the PEDI in the U.S.A., Slovenia, Puerto Rico or Sweden (4,99,103, 104). These were not randomized population-based studies, but convenient samples. The strength of this research is its population-based randomized data and its comparability with the results from the pilot study.

Can information bias have affected the results of Studies II and III? Did the parents and kindergarten teachers answer the questions in accordance with the child's true ability, and were the answers interpreted correctly? This is referred to as response bias/information bias, and data were collected using a standardized parental interview, not by observing children's behavior. The data were self-reported by the parents, and there might have been a possibility that parents have over-estimated or under-estimated their children's performance of ADL skills due to social norms. Could information bias explain the differences in age norms between the U.S.A. and Norway? In Norway it is not socially appropriate to assert oneself, and an information bias related to values of assertiveness may be affected by culture. However, similar deviations from the American normative values were found in the

Netherlands, Slovenia and Puerto Rico (117,103,101). All interviews were conducted by the same investigator, and intra-rater and inter-rater reliability were found to be excellent ( $r=0.95-0.99$ ).

Were the results of Paper II, III and IV influenced by other factors such as the respondents' education, occupational status or the mother's age? This is referred to as confounding factors in analysis. If an association is observed between factor A and result B, and this association of A and B may be a result of a third factor, C, this is then denoted as the confounding factor for the association. We could not detect any statistically significant differences for parent's education or mother's age. However, children of mothers working full-time scored significantly better related to functional skills in social functioning than children of home-makers in Paper IV.

That this research is representative of the population concerned is ensured to some degree as randomized techniques were used for including the sample in Studies II and III, which has reduced any bias in this respect. The sample corresponded well with the general Norwegian population in relation to mother's age, occupation, and education (with a slight over-representation of mothers with more than 16 years of education). In Paper IV, the results were drawn from a multi-stage random sampling procedure, which should have a certain degree of representativeness. We found that the results from the pilot study (Papers II and III) were largely comparable. The low response rate of 37 % is a limitation in the study, but in comparison with similar studies, we have a fairly good participation rate considering the expected participation rate from other population-based studies in Oslo.

Were sound methods used to apply the instrument in this study? This is referred to as internal validity. In this research, inter-rater and intra-rater reliability were found to be excellent, and the scoring criteria were found to be valid from the results presented in Paper II and IV. The results were similar, although the scoring criteria were revised.



## **5.5 Clinical implications for continued use of the PEDI in Norway**

The PEDI is one of the very few assessments that give information about the child's ADL performance in the context of the environment, and which direct intervention and evaluation toward children's participation in daily life. It is important to focus assessment, and thereby intervention, on children's participation in their own environment. An assessment directs health professionals' thoughts and thereby the interventions they choose. It is therefore important to use assessments that focus on interventions related to children's participation in everyday life. Without knowledge of the child's performance in its own environment, it is often not possible to design realistic and meaningful interventions. Interventions need to create a change in the child's everyday life. Therefore, the PEDI is a very important tool in pediatric habilitation. But what does the finding of deviation in age norms mean for the applicability of the PEDI in Norway?

A child's environment contains large variations related to physical factors, attitudes, support and domestic factors, all influencing performance of ADL skills. As a consequence this creates variations in normative values in different countries. The age norms from the US normative values cannot be used to assess whether a Norwegian child's functional status deviates from what is typically seen at that age. At least, for the items identified as deviating in Paper II and IV, a test result indicating a delay in development of approximately one year might not indicate a true deviation from other Norwegian children. As a consequence, a Norwegian age-norm scale needs to be developed in line with the results.

However, the criterion-referenced scores can still be used with no restrictions. The PEDI has the particular feature that it reports outcomes in two scales: normative scores and scaled scores. The scaled score provides an indication of the child's performance level in the content of the different domains in the PEDI. The scaled score is not adjusted for age and can be used to describe the function of children of any age, including those above 7.5 years. Thus, even

though the results of the Norwegian normative sample show that the norm-referenced scores need cultural adjustments, the scaled score is still useful. As the scaled score is a criterion-referenced measure of functional abilities, it can be used to describe the child's status, monitor change and plan treatment. The Norwegian version of the PEDI is reliable for use in Norway to assess functional skills and caregiver assistance, as well as for evaluation purposes among children with a disability both at individual and group level.

## **6 CONCLUSION**

The overall objective of this study was to translate the American PEDI into Norwegian and to assess the applicability and validity of this version. In the process of the validation, methodological challenges arose related to the translation of the PEDI into Norwegian from a multi-disciplinary perspective. Procedures for achieving functional equivalence were described and discussed. If a multi-disciplinary tool, such as the PEDI, is to be accepted and commonly used, the contextual settings of the professional groups in society at large should be taken into consideration in addition to linguistic phenomena in the native culture.

The applicability of the US reference values of the PEDI was examined in relation to the performance scores recorded in a sample of Norwegian non-disabled children. The results of the first applicability study showed that the influence of cultural values in children's performance deviated from the US PEDI values, and that the performance of the tasks and scores examined in the PEDI need cultural adjustment. Owing to the low sample size, the results called for a larger study. Therefore, a relatively large population-based randomized study was conducted to evaluate the applicability of the PEDI US normative data for a general Norwegian population. The study was also used to compare the results with those of the previous Norwegian studies. The results showed that the Norwegian sample scored significantly lower than the US reference values for functional skills and caregiver assistance,

especially for self-care. For mobility and social function, the results are of less significance. Specific items deviated from the US data, which may suggest that adjustments are necessary for the applicability of the PEDI in the Norwegian culture, which is in agreement with previous studies. There is a need to develop Norwegian normative values on the basis of the Norwegian normative sample.

The reliability of the PEDI was examined in relation to inter-rater, inter-respondent and intra-rater reliability in a sample of children without disabilities between 1.0 – 5.9 years of age in Norway. The results indicate that enhanced reliability was secured when the same interviewer interviewed the same respondent, as well as when two trained interviewers interviewed the same respondent. However, different respondents who know the child in different settings, for example parents and primary caregivers or other professionals, may differ in their understanding of the child's performance. The consistency of scores should therefore be reviewed when different respondents are interviewed. Children's capability in respect of self-care tasks is influenced by parents' expectations and the child's motivation, and thus seems to improve with additional attention. When evaluating the outcome of treatment for disabled children, this should be taken into consideration. Increased focus and use of the PEDI might, as such, increase children's independence in self-care skills.

The finding of this research highlights the importance of cultural validation of norm-referenced tests. The age norm deviated from the US normative values and cannot be used. Norwegian age norms need to be adjusted in line with the results of this research. The scaled score provides an indication of the child's ability to perform the total amount of tasks in the PEDI. The scaled score is not adjusted for age and can be used to describe the function of any age and evaluate change, including those above 7.5 years. Therefore, it is still useful.

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**CROSS-CULTURAL VALIDATION OF THE PEDIATRIC EVALUATION OF  
DISABILITY INVENTORY (PEDI) NORMS IN A RANDOMIZED NORWEGIAN  
POPULATION**

M. Berg, M.Sc. OT <sup>1</sup>, G. Aamodt, PhD <sup>2</sup>, J. Stanghelle, MD PhD <sup>3</sup>, L. Krumlinde-Sundholm  
PhD OT<sup>4</sup> A. Hussain, MD, PhD<sup>5</sup>

<sup>1</sup> Sunnaas Rehabilitation Hospital, University of Oslo, Norway

<sup>2</sup> Norwegian Institute of Public Health, University of Oslo, Norway

<sup>3</sup> Sunnaas Rehabilitation Hospital, University of Oslo, Norway

<sup>4</sup>Department of Woman and Child Health, Karolinska Institute, Stockholm, Sweden

<sup>5</sup> Institute of General Practice and Community Medicine, University of Oslo, Norway

Corresponding author:

Marie Berg

Dept. of Research

Sunnaas Rehabilitation Hospital

1450 Nesoddtangen

Norway

Direct line: +47 66 96 90 00

Fax: +47 91 25 76

E-mail: [Marie.Berg@Sunnaas.no](mailto:Marie.Berg@Sunnaas.no)

and

Sunnaas Rehabilitation Hospital

Faculty Division Ullevål University Hospital

University of Oslo

Pb 1130 Blindern

0318 Oslo

Norway

The Pediatric Evaluation of Disability Inventory (PEDI) is one of the most commonly used assessments for children with a disability. Normative data from the US are used for determining whether a deficit or delay exists with respect to functional skill development. The purpose of this study was to analyze cross-cultural validity of the PEDI American normative data for a general Norwegian population. A random selection of 174 typically developed Norwegian children between 1.0 and 5.9 years participated. The results for capability and care-giver assistance in the domains of self-care, mobility and social function ranged from a mean of 38.0-46.8 against an expected 50. The Norwegian sample scored significantly lower than the US reference values for functional skills and care-giver assistance, especially for self-care. For mobility and social function, the results are of less significance. Although living conditions in Norway seemingly do not differ from the US western style of life, differences were found in normative values. Specific items deviated, suggesting necessary adjustments for the applicability of the norm referenced scores of PEDI in the Norwegian culture. This finding highlights the importance of cultural validation of norm referenced tests. Even though interpretations of the normative score results must be done with some caution, the option of using the scaled scores of PEDI is useful and recommended to describe and measure abilities and to evaluate change. *Key words:* cross-cultural, validation, functional, assessment, children, outcome measure.

## INTRODUCTION

The Pediatric Evaluation of Disability Inventory (PEDI) was developed as a functional assessment and an evaluative tool for children with a disability from 6 months to 7 ½ years of age [1]. PEDI is described as a gold standard for functional assessment instruments [2, 3], and is one of the most commonly used assessments for children with a disability [4]. The PEDI was designed to detect whether a deficit or delay exists in children with respect to functional skill development and, if so, to describe the extent and content area of the delay or deficit. The PEDI provides outcome measures both as normative and scaled scores, which can be used to give functional descriptions and ability measures related to self-care, mobility and social function, as well as to evaluate change [1]. A normative score below 30 indicates that the child is delayed mastering functional skills in relation to the US standardization sample. PEDI has been translated into many languages [5-11]. Some validation studies have been conducted and certain cultural differences are noted [5-9].

Living conditions in Norway seemingly do not differ from the US western life style, and it might be assumed that the US age norms would be applicable in Norway. However, development of skills in everyday life is influenced by personal, social, cultural and environmental factors, in addition to the child's age and general development. Therefore, the individual child in the context of his/her environment is the unit of analysis, rather than the child's capacity of ADL skills. [12, 13]. There is good evidence of PEDI's content validity [14-16], reliability [17-19], and responsiveness to change [20-22]. However, to make interpretations of norm referenced results possible, both for individuals and to facilitate comparison of health-care in different countries, there is a need for measures to work in a cross-cultural consistent manner [23].

## Cross-cultural validation of PEDI

Cross-cultural validation in different cultures provides evidence of possible variability related to age norms and item responses. Randomized population based methods are preferred but have not been used in earlier studies [1, 5-9]. Hence, the purpose of this study was to analyze cross-cultural validity of the PEDI American normative data for a general Norwegian population.

## METHODS

### *Participants and sampling*

A total of 176 children aged 1-5.9 years from randomly selected kindergartens in Norway participated in the study. The age range was chosen since the self-care scale in the PEDI plateaus at approximately 5.5 to 6 years [24], and the mobility scale even earlier.

Kindergartens were randomly selected from 2 out of 19 counties. These counties were Oslo (urban) and Østfold (with mixed municipalities). Oslo consists of 15 townships with a varying number of kindergartens. To accommodate the socioeconomic differences, less and more affluent townships were stratified. From the remaining townships, 5 were selected from the less affluent and 3 from the more affluent townships following a simple random procedure. Kindergartens in Oslo were only included in this study if they had children in the age range 1-5.9 years. Thirty-four kindergarten fulfilled this criteria. Three of the kindergartens contacted decided not to participate. From the remaining 31 kindergartens, four were randomly selected to participate. All parents with non-disabled children age 1.0-5.9 years from the selected kindergartens were invited to participate. In Østfold county 14 municipalities had less than 15,000 inhabitants. With a view to recruiting children from small communities, 6 municipalities were randomly selected. In municipalities with less than 5 kindergartens, 1 was selected. If the municipality had more than 5 kindergartens, 2 kindergartens were selected.

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Following these criteria, we had 9 kindergartens, of which 8 participated. The response rate was 37 %.

A total of 478 children in the selected kindergartens were contacted, and 176 participated in the study. Two children were excluded because of mental or physical disorders. Adopted children, or children with two foreign-born parents, were excluded from the sample. Previous studies have shown that adopted children may have a developmental functional delay [25]. Parents might influence cultural values related to self-care, mobility and social function of the child [26].

### *Interviews*

During interviews, 138 mothers and 8 fathers participated alone. There were 26 couples along with 2 grandmothers. The mean age of the mothers was 34 years (range 24-45), and the mean age of the fathers was 35 years (range 30-46). All interviews were conducted by the first author and lasted approximately 60 minutes. Parents were interviewed in accordance with their preferences, either in kindergarten, at home, or at their workplace. Each interview started with the interviewer reading the scoring criteria and clarifying questions. It was explained that in the PEDI interview, children between 1.0 and 7.5 years are asked the same questions regardless of age, and that mastery of all items was not expected. It was explained that the purpose of the interview was to find the variation in children's capability and performance related to the items. Parents were also asked whether the items were relevant for their child.

### *Measures*

Procedures for cross-cultural adaptation following guidelines by Guillemin et al. [27] were used in translating PEDI to Norwegian [28]. In an earlier study, the applicability of the Norwegian version of the PEDI was investigated in a sample of 52 non-disabled children, and some deviations were found [9]. Questions were raised concerning whether the deviations

from the US reference values were due to somewhat altered scoring criteria for capability. Therefore, the wording of the scoring criteria was revised and one of the developers of the PEDI confirmed the translation. The revised translation of the scoring criteria was used in this study. Reliability of the translated version showed excellent agreement of the observations (ICC 0.64-0.99) [29].

PEDI results were collected as raw scores according to directions in the manual. The raw scores obtained were compared to the Normative standard scores given in the manual [1]. These scores are based on a normative sample of 412 typically developing US children. The assessment includes different sets of reference values. Tables list the age ranges at which Functional Skills items are mastered by 10%, 25%, 50%, 75% and 90% of specific age groups in the US normative sample [1]. The normative standard scores were constructed to have a mean of 50 and a standard deviation of 10 in each age group. Ranges of standard scores and means and standard deviations for each 6-month age group are listed in the PEDI manual [1]. The normative standard scores provide an indication of the child's age-related skills. Normative standard scores can be used to identify children with functional delay, as few typically developed children are expected to have normative standard scores below 30.

### *Scales*

The investigated scales were:

*Functional Skills Scales:* The 197 items were scored 'unable' (0) or 'capable' (1). The scoring criteria for capable was "1= can perform: the child performs the task in most situations or behaviours are previously mastered but no longer required or used."

*Caregiver Assistance Scales:* The 20 items were scored on a six point scale ranging from independent, to supervision, minimal help, moderate help, maximum and total help.

### *Ethics*

The Regional Committee for Medical Research Ethics, Health Region South, and the Data Inspectorate approved this study. Participation was voluntary. All parents in the kindergarten received a written invitation. To confirm their participation, the parents returned the response form. Verbal information about the purpose of the study was provided to the parents prior to the interview. They were informed that they could withdraw from the study at any stage.

Participants received a children's book as gratification.

### *Data analysis*

The six PEDI subscales were summed up and described with mean values, standard deviations and range distributed for age intervals of 6 months from 1.0 -5.9 years. For each item and within each age group, the distribution of the percentage of children managing the tasks was computed and compared with the normative values. To compare the mean of 50 and the observed scores, one sample *t*-test was used. Independent sample *t*-tests or ANOVA tests were used to compare the results from subgroups such as boys and girls, mother's education and rural/urban sites. A *p*-value less than 0.05 was considered statistically significant. The SPSS (12.0) software package was used for data registration and statistical analyses.

## RESULTS

### *Respondents*

Fifty percent of the respondents worked full-time, 19% part-time, 13% were home-makers, 11% were on maternity leave, 5% were students, and 3% were on sick leave. Twenty-two of the parents had 12 or less years of education, 41% had 13-15 years of education and 37% had 16 or more years of education. The sample in this study appeared to correspond well with a general Norwegian population, with a slightly higher proportion of mothers with more than 16

years of education. According to Statistics Norway [30], 83% of females aged 30-34 are working, whereas 80% of the sample worked. Twenty-two percent had an educational level of <12 years, the same as in the sample. In Norway, 54% of the females have 13-15 years of education, whereas 41 % of the sample had this level of education. Twenty-four percent of Norwegian women have more than 16 years of education, whereas more than 37% of the sample, were at this level.

There was no relation between the results and the parent's length of education. Seventy-five percent of the parents did not report any chronic illness for their child. However, parents reported that 2% of the children had asthma, 10% had an allergy, and 3% had both asthma and an allergy. Nine percent had other illnesses. There was no difference between the groups who reported illness and who did not. Thirty-six percent of the sample had one or no younger sibling, 18% had older siblings more than four years old, and 44% had older siblings who were not more than four years old. No differences were found which related to rank or number of siblings.

### *Outcome normative data*

#### *Self-care*

Summary statistics for the self-care: functional skills are shown in Table I. The Norwegian sample scored significantly lower than the PEDI references, both for the functional skills scale (mean 40.1 versus expected 50,  $p<0.001$ ) and the caregiver assistance scale (mean 38.3 versus expected 50,  $p<0.001$ ). Normative standard scores are considered normal within the range 30.0-70.0, according to the manual [1]. Sixteen percent ( $n=27$ ) of the sample scored <30 in self-care, for both functional skills and caregiver assistance, versus an expected 2%. Of those, 67% were boys. Only two children (1%) scored <25 in self-care: functional skills. However, 9 % ( $n=16$ ) of the sample scored <25 in self-care: caregiver assistance. Boys scored significantly lower than girls, as shown in Figure 1, in terms of functional skills in self-care:



normative standard scores (means 41.6 and 38.4,  $p=0.01$ ), but not related to the self-care: caregiver assistance scale (means 39.5 and 37.1,  $p=0.07$ ). The age distribution of when the children first managed the different items on the functional skills scale was different from what was expected from the PEDI reference values (Table I). For some of the items the ability changed in an inconsistent way between the age groups (values not shown). For items related to eating, the Norwegian sample and the reference had no deviation in scoring. But in respect to grooming and bathing, most items deviated from the norms. For grooming, all items related to tooth brushing, as well as the majority of items related to hairbrushing, nose care, hand, body and face washing were mastered at least one year later by the Norwegian sample. The parents commented that they perceived independent mastery of many of these items to have little importance, and some of them as less relevant. For example, Norwegian parents are told by the dentist to help brush children's teeth thoroughly until 10 years of age. Boys often have short hair, so managing tangles and parting hair is not an issue for them. Most children's shoes had Velcro straps and not shoelaces.

All items but one related to pullover/front opening garments correlated well with the normative values. But items related to buttoning and managing zippers were mastered one year later by the Norwegian sample. The items related to shoes/socks correlated well with the normative values except for tying shoelaces. The majority of items related to toileting and bladder and bowel management was mastered 6-18 months later than the normative values.

For the caregiver assistance scale, many areas deviated from the normative values. Grooming, bathing, dressing the upper body, dressing the lower body and toileting were all mastered 1-23 months later than the normative values. According to the reference values for bladder and bowel management, >10% of the US sample were independent at age 2.0-2.5 years. However, less than 10% were independent at this age in the Norwegian sample. The timing when 50% and 90%, respectively, of the children had achieved continence was

approximately one year later in the Norwegian sample compared with the US reference norms. Concerning caregiver assistance for managing bladder continence, 50% in the US sample were independent at age 3.0 – 3.5 years whereas while the Norwegian children reached this level at 4.0 – 4.5 years of age.

### *Mobility*

Summary values for the mobility scale are given in Table II. In mobility tasks the Norwegian sample scored significantly lower than the PEDI reference values, both for the functional skills scale (mean 43.9 versus expected 50,  $p<0.001$ ) and the caregiver assistance scale (mean 46.5 versus expected 50,  $p<0.001$ ). Eight percent ( $n=14$ ) of the sample scored  $<30$  in mobility: functional skills. Four percent ( $n=7$ ) scored  $<30$  in mobility: caregiver assistance. However, only one percent ( $n=2$ ) scored  $<25$  in mobility: functional skills, and one percent ( $n=2$ )  $<25$  in mobility: caregiver assistance.

For items on the functional skills scale, the Norwegian sample mastered all items related to toileting six months later than the normative values. As many children used diapers until 3-3.5 years, items related to toilet transfers were not relevant or attempted. Items related to transfers in and out of the car were mastered approximately one year later than the normative values. Parents reported that they fastened the child's seatbelt, and many had automatically locking car doors for safety reasons. Thus, items concerning opening and closing the car door were not relevant related to age. Many also had vans, which prohibited the child from climbing in/out of the car themselves because of their size. All items related to on/off toilet/chair/bed: use of no arms showed a lack of fit. For safety reasons, managing seat belt and transfer in/out of the bathtub was often done by parents.

For the care-giver assistance scale, discrepancies were observed related to the car transfer item, in what the Norwegian sample was six month to one year later in achieving

independence. However, the Norwegian sample was independent one year earlier than the US norms related to indoor and outdoor locomotion.

### *Social function*

In the domain of social function, the observation values were only somewhat lower for normative standard scores of functional skills (mean 46.6 versus expected 50,  $p<0.001$ ) and for caregiver assistance (mean 46.8 versus expected 50,  $p<0.001$ ). For the functional skills scale, deviations from the normative standard scores increased with increasing age, as seen in Table III. Only one child scored below 30 in the caregiver assistance scale.

On several items the children in the Norwegian sample matured one year later than the reference population: understanding directions, naming things, describing problems/feelings, simple pretend play, simple time concepts. Two items showed a major discrepancy with the US norms: “keeps track of schedule” and “consistently initiates household chores”. Many parents said that they felt these two items were less relevant for pre-school children in Norway.

Some items were managed one year earlier in the Norwegian sample: “can direct an adult to help child return home”, “goes about familiar environment outside of home with only periodic monitoring for safety”, and “follows school guidelines”. In all other items in this domain, the Norwegian sample score concurred well with the PEDI reference values. For the caregiver assistance scale, there was a discrepancy related to functional comprehension, in which the Norwegian sample was independent one year later than the reference values.

There was a significant difference among parents working full-time and homemakers regarding social function: functional skills ( $p=0.01$ ), and a difference regarding social functioning: caregiver assistance ( $p<0.10$ ) with the children of parents working full-time scoring better than children of homemakers.

## DISCUSSION

This study compares US normative values for the PEDI with PEDI values in a representative Norwegian population. The Norwegian sample scored significantly lower compared with the US reference values, especially related to self-care, and the deviation increased with age. So, how can this delayed timing for mastery of skills be explained? Are Norwegian children in general delayed?

The most significant difference between the Norwegian and the US samples was found in the use of diapers. Seventy-five percent of the Norwegian children were continent in daytime at 48 months of age, which is 12-18 months later than the US normative group. In Sweden a similar trend was also seen in a recent longitudinal study of bladder control in healthy children, which found the median age for attaining daytime and night time dryness to be 42 months and 48 months, respectively [36]. There may be several reasons for this. Diapers have developed since the standardization of PEDI about 15 years ago. They now feel dry even when they are soiled, making them less uncomfortable and also making cause and effect less obvious for children. Scandinavian cultural values emphasize not stressing the child with early toilet training, but rather waiting until the child is perceived 'ready' for this. Perhaps an earlier start of toilet training in the US could explain the finding, however, at age 4.5 – 5.0 years old 90% of both Norwegian and US children stayed dry day and night.

Several other items in the PEDI may be related to toilet training onset. The prolonged use of diapers means that children are also helped to take off/on pants, and with zipping and buttoning at higher ages, since the adults anyway are involved in the procedure. Thus the child may not be encouraged to participate in these components of the dressing activities either. In general, girls mastered self-care skills earlier than boys, a finding also present in studies from the Netherlands and Slovenia [7, 8].

Another area where norm differences were found was in the domain of mobility. This difference was related to use of arms in transfers on/off toilet, on/off chair, in/out of bed, gets in and out of tub, gets in and out of car, and manages seatbelt deviated. In children above 3 years of age, mean values become highly affected by items related to the use of arms, because the other transfer items are earlier achieved. If these items were not accounted for, the Norwegian normative values would not deviate. Parents generally commented that they had not really paid attention to whether their child used arms or not in transfers, thus their responses may be unreliable. Furthermore, elevated cars, modern car locks, and child seats with complicated locking affected transfers in/out of cars and might be different from those in use when the PEDI was developed. In 2005 Haley et al. found [38] that items tapping the use of the upper body for mobility are potential candidates for revision or removal in future work with the scale. We strongly agree with this.

In the domain of social function, items related to regularly checking or asking about the time and consistently initiating household chores deviated from the US norms. These items were all perceived as less relevant by Norwegian parents. Moreover, parents often found it difficult to differentiate between the examples in the manual concerning different levels of assistance needed for functional comprehension and problem-solving.

Specific items were found to deviate from the US normative values, which indicate that norm values for these items should be adjusted to fit normal distribution relevant to the Norwegian culture. The current norms cannot be used to interpret functional developmental delay with good precision. Changing, adding or removing items, will change the properties of the instrument, and a valid comparison of results in different countries will be difficult. A comprehensive perspective on such changes is necessary and must be performed in consultation with the original authors.

The strengths of this study are its population-based randomized data sampling and response rate. Children were randomly selected from a stratified socio-economic, urban/mixed municipality population and geographical neighbourhood in Norway. All interviews were conducted by the same investigator. Due to feasibility reasons, 2 out of 19 counties were selected representing both an urban and mixed population. The response rate was 37%, which is comparable with other population-based studies conducted in Oslo and elsewhere in Europe [31-34]. In the Dutch standardization, the sample ( $n=1849$ ) was large but had a response rate of 17%. This reflects the difficulties involved in engaging participants in this kind of study [31]. Nordmark et al. [5] used a convenience sample ( $n=52$ ) in a selected population. The Swedish results deviated less from the norm than the Norwegian. A possible reason for this might be the use of a smaller and non-population-based sample. Groleger Srsen et al. [8] recruited data from parents and children visiting a health care centre for regular check ups. This was a convenient sample, and the response rate was not reported. In comparison, the US normative data reflect demographic characteristics from the US census bureau. No data on response rate were given [1]. Our study population corresponds well with the demographics of the Norwegian population [30]. Previous studies have not applied strict population-based design in data sampling. A low response rate may imply a bias in sample selection since there might be a tendency that parents who were satisfied with the development of their child, and secure in their role as parent more often agree to participate in this type of study [35].

### *Cultural influence on functional performance*

Ages and Stages is a parent-completed developmental screening with US normative data that has been evaluated in a Norwegian population sample ( $n=2534$ ). In this study, Norwegian children were somewhat later in putting on their shirt and buttoning than were US children. In this screening, Norwegian parents' reports about their children's development was very

similar to the US sample. However, in this instrument continence was not measured [39]. In our study several parents considered items related to grooming and dressing less relevant and the low Norwegian PEDI mean score might be a reflection of this attitude.

There seem to be differences concerning PEDI normative values between different cultures. Qualitative and quantitative data analysis confirmed socio-cultural influences and differences of performance of functional skills between the US norms and children in Puerto Rico [40, 41]. The Norwegian children were independent in self-care at a later stage, than the US, Swedish, Dutch and Slovenian normative values [1, 5, 7, 8]. However, indoor and outdoor locomotion matured earlier among children in Norway. This is in accordance with Norwegian habits of regular family hiking. Compared with Dutch normative values [42] Norwegian results for social functioning strongly concurred on both capability and caregiver assistance.

### *Implications for clinical use*

PEDI has the particular feature to report outcomes in two scales, normative scores and scaled scores. The scaled score provided an indication of the child's ability to perform the total amount of tasks in the PEDI. The scaled score is not adjusted for age and can be used to describe the function of children of any age, including those above 7.5 years. Thus, even though the norm referenced scores may need cultural adjustments and should be interpreted with care, the scaled score is still useful to measure functional abilities, monitor change and plan treatment. The purpose of this study was to analyze cross-cultural validity of the PEDI American normative data for a general Norwegian population.

## CONCLUSION

Although living conditions in Norway seemingly are very alike other western countries like the US, norm values for functional skills acquisition deviated as a function of cultural differences. The Norwegian sample scored significantly lower compared with the US

## Cross-cultural validation of PEDI

reference values, especially related to self-care, and some test items were viewed to be irrelevant by Norwegian parents. The US PEDI age norms needs to be used with caution and some adjustments of the scales are needed to establish age-relevant Norwegian norms. The PEDI measures functional performance in a relevant environmental context, but consequently the child's performance is influenced by culture, which creates variation in normative values. However, the PEDI scaled scores are useful and applicable for guiding treatment and evaluating change. The findings in this study highlights the need for cultural validation of instruments also between similar cultures.

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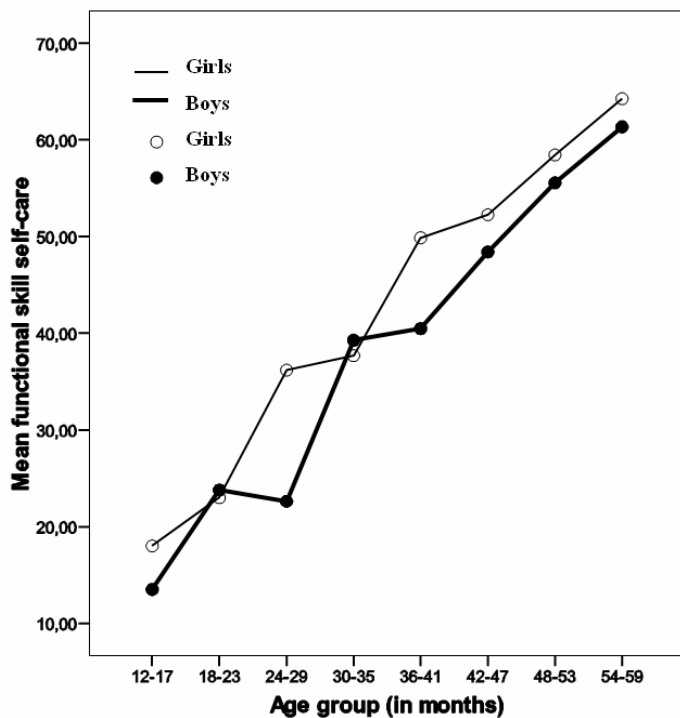
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Table I. *Norwegian sample results for Self-care: Functional skills and Caregiver Assistance (n=174)*

Age groups	n	Functional Skills				Caregiver Assistance			
		Mean	SD	Range	p-value*	Mean	SD	Range	p-value*
1.0-1.4	4	51.6	5.2	47-57	0.582	46.2	0	46	0.001
1.5-1.9	16	41.2	7.4	26-56	0.001	42.3	6.5	31-50	0.001
2.0-2.4	18	41.9	7.1	27-53	0.001	39.9	6.2	27-51	0.001
2.5-2.9	20	42.9	7.5	31-58	0.001	38.2	6.6	26-51	0.001
3.0-3.4	16	40.4	6.7	29-51	0.001	33.2	11.7	14-54	0.001
3.5-3.9	18	37.6	8.1	23-50	0.001	33.8	12.1	10-47	0.001
4.0-4.4	18	36.7	6.1	25-50	0.001	32.1	8.7	10-46	0.001
4.5-4.9	18	37.9	11.0	25-74	0.001	42.4	10.9	25-78	0.001
5.0-5.5	24	40.3	5.4	32-48	0.001	41.7	5.0	33-55	0.001
5.6-5.9	22	39.2	5.4	31-51	0.001	35.9	7.6	22-54	0.001
Total sample	174	40.1	7.5	23-74	0.001	38.3	9.1	10-78	0.001

Means, standard deviations and ranges of normative standard scores in age groups and total sample.

\*The p-value is a result of comparing the normative sample with the expected/standardized sample score equal to 50.



*Fig. 1.* Comparison of girl's and boy's functional skills in self-care. Dot/lines show means of functional skills in self-care. Error Bars show 95.0% CI of Mean.

Table II. *Norwegian sample results for Mobility: Functional Skills and Caregiver Assistance (n=174)*

Age groups	n	Functional Skills				Caregiver assistance			
		Mean	SD	Range	p-value*	Mean	SD	Range	p-value*
1.0-1.4	4	54.7	2.2	52-58	0.03	56.7	0.8	56-58	<0.01
1.5-1.9	16	48.8	9.2	27-67	0.60	50.2	6.1	38-58	0.91
2.0-2.4	18	43.4	8.0	33-60	0.01	44.2	10.2	30-66	0.03
2.5-2.9	20	46.4	8.8	29-63	0.08	44.2	7.0	33-58	0.01
3.0-3.4	16	40.8	5.0	31-51	<0.01	44.8	5.5	35-52	0.01
3.5-3.9	18	41.2	4.5	33-50	<0.01	47.1	7.6	36-71	0.12
4.0-4.4	18	40.4	6.4	28-55	<0.01	45.8	7.5	38-61	0.03
4.5-4.9	18	38.5	10.5	24-61	<0.01	47.8	8.2	38-59	0.28
5.0-5.5	24	49.8	9.1	31-60	0.91	50.1	9.8	36-59	0.97
5.6-5.9	22	41.3	12.5	18-54	<0.01	42.6	13.6	18-53	0.02
Total sample	174	43.9	9.4	18-67	<0.001	46.5	9.1	18-71	<.001

Means, standard deviations and ranges of normative standard scores in age groups and total sample.

\*The p-value is a result of comparing the normative sample with the expected/standardized sample score equal to 50.



Table III. Norwegian sample results for Social Function: Functional Skills and Caregiver Assistance (n=174)

Age groups	n	Functional Skills				Caregiver assistance			
		Mean	SD	Range	p-value*	Mean	SD	Range	p-value*
1.0-1.4	4	51.7	6.3	43-57	0.64	50.1	5.2	46-56	0.86
1.5-1.9	16	51.9	10.2	35-74	0.46	46.5	6.3	28-54	0.04
2.0-2.4	18	51.3	8.5	38-63	0.52	43.5	6.1	33-54	<0.01
2.5-2.9	20	49.5	9.4	34-62	0.81	45.6	7.0	35-61	0.01
3.0-3.4	16	47.3	4.6	39-55	0.03	44.1	7.2	34-57	0.01
3.5-3.9	18	44.8	5.2	36-54	0.01	44.5	5.5	32-54	0.01
4.0-4.4	18	43.7	6.5	33-53	0.01	47.4	10.6	32-74	0.30
4.5-4.9	18	43.1	12.1	30-76	0.03	45.6	9.0	31-69	0.06
5.0-5.5	24	45.0	6.1	36-61	0.00	50.2	7.8	37-66	0.89
5.6-5.9	22	43.4	6.7	32-60	0.00	50.9	8.4	35-64	0.61
Total sample	174	46.6	8.4	30-76	0.01	46.8	7.9	28-74	0.01

Notes: Means, standard deviations and ranges of normative standard scores in age groups and total sample.

\*The p-value is a result of comparing the normative sample with the expected/standardized sample score equal to 50.

